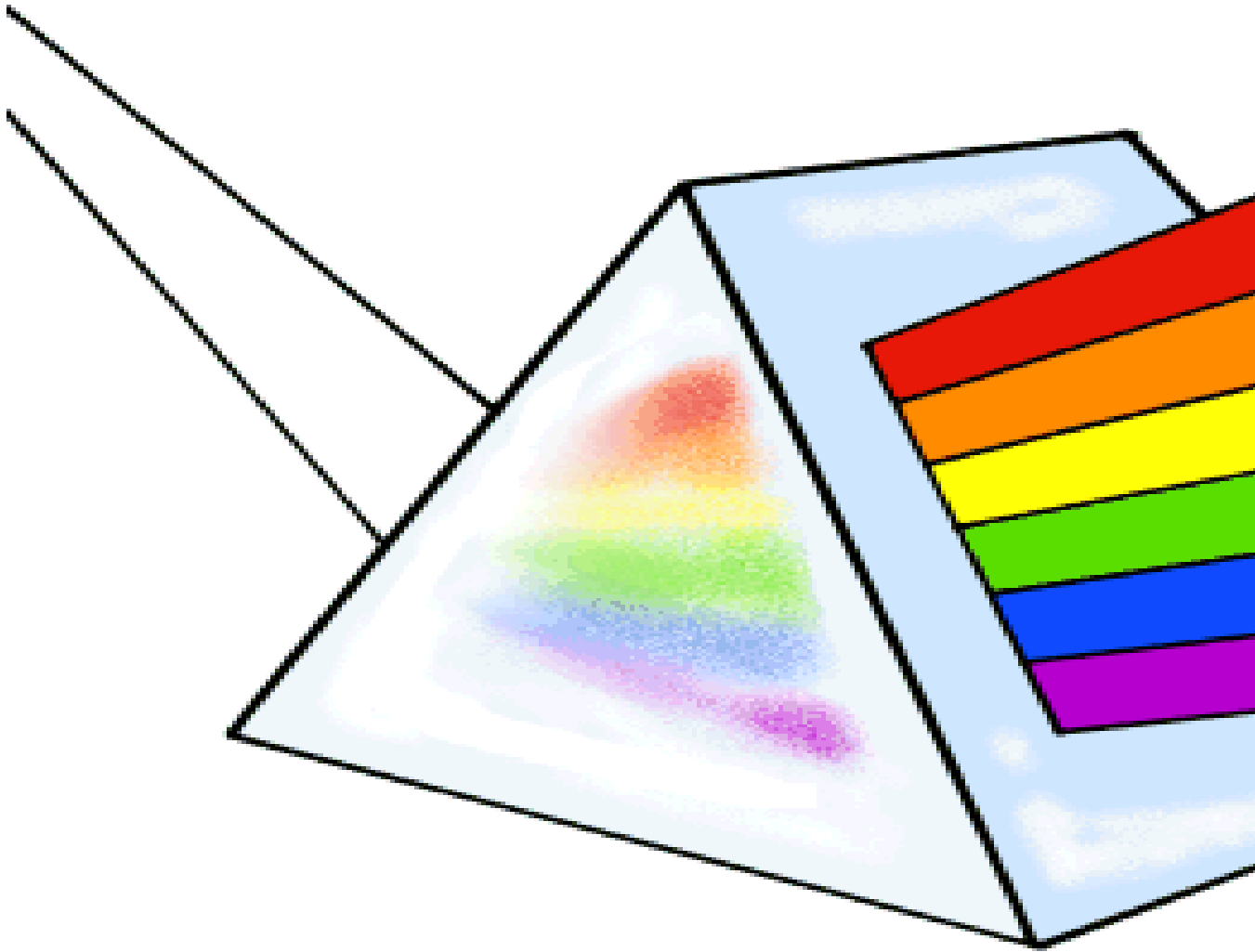


Missouri 2004 Traumatic Brain Injury Needs Assessment



Missouri Head Injury Advisory Council

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Executive Summary

This TBI Needs Assessment was conducted to describe the breadth and depth of need among persons with TBI and their families throughout Missouri. The goals of this needs assessment are the following:

GOAL I: ESTIMATE THE INCIDENCE & PREVALENCE OF TRAUMATIC BRAIN INJURY IN MISSOURI

GOAL II: INTERVIEW INDIVIDUALS WITH BRAIN INJURY, THEIR FAMILIES, AND OTHER KEY STAKEHOLDERS

GOAL III: IDENTIFY BRAIN INJURY SERVICE GAPS IN MISSOURI

WHO PARTICIPATED IN THIS NEEDS ASSESSMENT?

A key feature of this needs assessment is that it did not rely primarily on written surveys, which are problematic because they tend to be sent only to people who are already well-connected with the TBI service system (e.g., through Brain Injury Association membership lists and similar organizations). Even among that TBI service-savvy population, response rates for written surveys tend to be modest, and therefore do not represent the needs of TBI survivors and families who are not as well-connected.

This study worked to remedy this bias by relying on outreach to various groups who would more likely represent the actual population of persons with TBI. For example, we supplemented Brain Injury Association contact lists with lists of recent inpatients with TBI, recent outpatients with TBI, community organizations who do outreach to persons with TBI, and urban and rural outreach to underrepresented populations.

HOW DID MISSOURIANS PARTICIPATE IN THIS NEEDS ASSESSEMENT?

This needs assessment did not rely on written materials such as surveys, because surveys may be difficult for some TBI survivors to understand and complete. Instead, this project conducted more time-intensive but necessary in-person and phone interviews that lasted from 30 minutes up to 1 ½ hours. These interviews, combined with new focus group

data, enabled the project to have an accurate view of the wide range of needs among persons with TBI.

HOW MANY MISSOURIANS HAVE A BRAIN INJURY?

The primary findings of this study suggest that incidence estimates for TBI in Missouri's population vary widely. However, given the most recent data available from the TBI Registry and the CDC, and accounting for the numerous biases toward under-reporting, the best estimates suggest that a total of between 18,300 and 24,832 will incur a brain injury each year, although only about one quarter of that number will be hospitalized for TBI, and a relatively smaller proportion will experience lifelong TBI-related disability. In 2004, an estimated 114,089 Missourians alive today have ever been medically treated for TBI. This report offers a number of relatively straightforward suggestions to ensure that Missouri's incidence and prevalence data are in keeping with CDC guidelines and are as accurate and current as they can be given the limited resources available.

WHAT CONCERNS DID TBI STAKEHOLDERS RAISE?

The stakeholder needs assessment consisted of two parts: 1) extended phone and in-person interviews with TBI adult and child survivors, family members, and TBI service providers; and 2) a statewide series of focus groups among key stakeholder groups. By far the most common issues raised were related to *lack of TBI knowledge among agencies and service providers with whom persons with TBI must interact* (schools, human services state agencies, health care providers, etc.). A second key issue related to *poor service integration* across state agencies and other service providers. Another main theme related to *service accessibility*. Many participants reported that even where appropriate services may exist, barriers such as difficulty navigating the system, transportation problems, or funding issues interfered with delivering appropriate services in a timely manner. The following key barriers were listed by participants:

- **Limited public knowledge of TBI,**
- **Lack of coordinated state TBI policies,**
- **Funding issues,**
- **Lack of post-acute TBI services,**
- **Lack of adequate family supports, transportation, and housing,**

- Substance abuse,
- Traditionally underserved populations.

WHAT CHANGES CAN BE MADE TO IMPROVE MISSOURI'S TBI SERVICES?

The result of this needs assessment is a description of issues ranging from how to estimate the population in need of TBI services in the most cost-effective manner to how Missouri can ensure that children with TBI return to schools that are prepared to serve them. This report makes numerous recommendations for various TBI constituencies to consider in order to increase the effectiveness of their considerable efforts. In relation to the key barriers, the primary recommendations are the following:

Barriers	Recommendations
1. Lack of accurate TBI Incidence & Prevalence Estimates	<ul style="list-style-type: none"> • Improve Resources to Maintain Existing TBI Databases • Expand TBI Reporting Mandate to Acute Rehabilitation Hospitals • Supplement Hospital-Based Data with Community Survey Data
2. Limited Public Knowledge of TBI	<ul style="list-style-type: none"> • Create uniform educational materials on TBI • Create one uniform Missouri TBI website • Initiate marketing campaign to promote awareness of the single site • Require annual training in TBI for state employees and ongoing education • Offer TBI presentations at the state and regional conferences of other professions • Designate staff member in district offices to be the TBI-designated service provider • Utilize existing telehealth networks to increase accessibility • Identify celebrities who can promote services for persons with TBI • Advocate to restore funding to the Center for Innovations in Special Education
3. Lack of Coordinated State TBI Policies	<ul style="list-style-type: none"> • Develop a TBI Advocacy Network with participants from all TBI constituencies • Develop a legislative agenda for those issues that need to be addressed • Develop a TBI grassroots network, with individuals from each county in the state • Develop a TBI grassroots legislative listserv • Identify legislators who are willing to sponsor TBI-related legislation • TBI advocacy agencies consider hiring a

	<ul style="list-style-type: none"> part-time lobbyist • TBI Advocacy Network request meetings with relevant state agencies • TBI Advocacy Network request meetings with state agencies • Arrange MU Post-Acute Network
4. Funding Issues	<ul style="list-style-type: none"> • Insurance policies conceptualize TBI as a condition that requires long-term services • Demonstrate efficacy of services through pilot and demonstration projects • Increase the number of TBI service coordinators • Conduct demonstrations projects • Members of the TBI Advocacy Network meet with insurance and managed care • Conduct analysis to determine Missourians seeking TBI-related treatment and costs • Increase the number of such TBI-related programs in the state and visibility
5. Lack of Post-Acute TBI Services	<ul style="list-style-type: none"> • Promote conceptualization of TBI as a chronic health condition • Promote a case management system for persons with TBI • Each Regional Center employ a case manager with expertise in TBI • Convince state and private insurance providers of benefits of programs • Provide TBI continuing education programs to professional associations • Expand debt forgiveness programs for rehabilitation professionals • Educate rehabilitation professionals of existing federal debt forgiveness programs
6. Lack of Adequate Family Supports, Transportation, and Housing	<p><i>Housing Issues</i></p> <ul style="list-style-type: none"> • Partner with agencies that provide housing for persons with developmental disabilities • Greater partnership between TBI service coordinators and ILCs • Examine Medicaid waiver program eligibility criteria • Develop group home options for persons with TBI in the community <p><i>Family Support Issues</i></p> <ul style="list-style-type: none"> • Evaluate the existing Early Support Partnership Program • Examine the structure and implementation of intervention programs in other states • Develop resource packets to distribute at all hospitals • Develop a website that lists all available family supports by county • Work with the MO Brain Injury Association to form support groups in rural areas • Work with the Missouri Telehealth Network

	<p>to coordinate state-wide TBI support groups.</p> <p><i>Transportation Issues</i></p> <ul style="list-style-type: none"> • Develop and evaluate efficacy and cost-effectiveness of transportation models • Develop novel hybrid public-private partnerships • Develop web-based resources that list all transportation options by community • Re-evaluate existing Medicaid transportation reimbursement policies • Work with Medicaid to improve the timeliness of payments for Medicaid • Work with DVR to evaluate home-based work options for individuals with TBI • Work with state TBI researchers to propose transportation demonstration projects
7. Substance Abuse	<ul style="list-style-type: none"> • Advocate for more CSTAR programs specifically for persons with TBI • Improve marketing for the existing substance abuse program at MRC • Require annual training regarding TBI for DMH substance abuse counselors • Improve behavior management programs in substance abuse programs • Improve the integration of substance abuse services into existing TBI treatment
8. Traditionally Underserved Populations	<ul style="list-style-type: none"> • Formation of a pediatric special interest group of the MOHIAC • Update MO-BIA database for self-identification as a racial or ethnic minority • MOHIAC and BIAMO partner with MU's Extension office to reach rural areas • Develop and distribute a very brief handout listing resources for mild TBI
9. Statewide TBI Action Plan	<ul style="list-style-type: none"> • Key stakeholder groups form partnership to put in place an action plan with key goals, timelines, and specific objectives and designees responsible for activities

Key issues often involved challenges related to funding, but an effort was made to generate recommendations that have maximal impact-to-investment ratio by “piggybacking” on existing service structures wherever possible. The result is a blueprint for improving Missouri’s TBI services as we embark on the 21st century, one we hope will generate considerable interest among the many Missourians affected by brain injury.

I. Introduction

A. Definition of Traumatic Brain Injury

Throughout this report, the definition of traumatic brain injury used is as follows:

“Head injury” or “traumatic head injury”, a sudden insult or damage to the brain or its coverings, not of a degenerative nature. Such insult or damage may produce an altered state of consciousness and may result in a decrease of one or more of the following: mental, cognitive, behavioral or physical functioning resulting in partial or total disability. Cerebral vascular accidents, aneurisms and congenital deficits are specifically excluded from this definition (RSMo. 192.735).

B. Purpose

In relation to the goals and objectives, the purpose of this needs assessment is to estimate the population of persons with brain injury in Missouri, and to clarify needs and resources to meet the needs of persons with TBI and their families.

To address these goals, the needs assessment used multiple data sources and methods. These sources and methods include data from the trauma registry, the Department of Elementary and Secondary Education, Emergency Room audits, acute rehabilitation hospital audits, Missouri Model Brain Injury System data, jail and prison data, and population surveys to estimate the incidence and prevalence of TBI in Missouri.

Moreover, the project team surveyed and interviewed individuals with brain injury, their family members/guardians, and service providers throughout the state of Missouri. Surveys were developed from HRSA grants in Maryland and Iowa to conduct interviews with persons with TBI and their families. The interviews addressed demographic characteristics, cause of injury, current health status, behavioral disruption, injury severity, employment status, health care resources, and service needs and barriers.

Lastly, the project team attempted to identify brain injury service gaps in Missouri. The project team used the service matrix developed in 1999 by a number of state agencies serving persons with TBI. In addition, the study made use of other existing sources of information, such as focus group information, brain injury support groups, and new interviews and focus groups conducted among persons with TBI, their family members, service providers, and state agencies.

C. Goals and Objectives

The following needs assessment objectives were developed by the Missouri Head Injury Advisory Council (MHIAC) for the Needs Assessment Project. For each area, this report summarizes key findings and recommendations for improvement:

1. Estimating the Population of Persons with Brain Injury in Missouri
 - a. Examine and evaluate data from multiple data sources to develop an estimate of annual incidence and prevalence of TBI, focused on persons most likely to require subsequent state or private support services.
 - b. Conduct an assessment of emergency room reporting methods, acute rehabilitation hospital procedures, and TBI reporting within state and county corrections facilities. Make recommendations for actions to improve the accuracy of TBI reporting to the trauma registry.
 - c. Identify gaps in the existing data sources and assess best practices for collecting incidence and prevalence data among other states.
2. Surveying/Interviewing Individuals with Brain Injury and their Family Members
 - a. Using survey materials developed in previous HRSA grants in Maryland and Iowa, conduct statewide telephone surveys among persons with TBI and/or their family members/guardians. A representative proportion of telephone surveys should relate to the issues of minorities and children.
 - b. Conduct focus groups among persons with TBI and among family members/guardians of persons with TBI, in partnership with the Brain Injury Association of Missouri's statewide support groups. Areas of emphasis should include but are not limited to: service needs, needs of minority populations, needs of both adults and children, transportation, financial adjustment associated with independent living, effects of recent state funding changes, and preferences for future TBI-related educational/conference programming.
 - c. Identify needs and gaps in the areas of counseling (all types), peer mentoring, crisis intervention, respite care, and maintaining supportive family relationships.

3. Identifying Brain Injury Service Gaps in Missouri

- a. Using existing data sources (e.g., Dept. of Health and Senior Services Bureau of Special Health Care Needs Head Injury Service Coordinator Program survey report, interagency service matrix, report of the legislative task force on TBI, and other relevant documents) and information from survivor and family focus groups, identify service gaps across agencies, across the course of recovery from TBI, and across relevant populations (e.g., survivors, family members).
- b. Identify barriers to addressing these service gaps and characterize possible solutions to meet these needs.
- c. Assess differences in TBI definitions, program eligibility, and other factors related to interagency collaboration.

D. TBI in Missouri: Some Background and Policy Initiatives*

The Bureau of Special Health Care Needs within the Department of Health and Senior Services (MOBSHCN, 2004a) is the lead agency for TBI in Missouri, seeking to implement and improve existing state/federal programs in order to better serve individuals with TBI through changes in legislation, policy, and staff training. To fill in TBI service delivery gaps, state funding has been appropriated specifically for services and supports for individuals with TBI and their families. Based upon efforts of the Joint Interim Committee on Head Injury, legislation passed in 1985 for funding to be allocated in FY 1986 for transitional living rehabilitation services for individuals with TBI and to the Missouri Department of Health for brain injury services. Furthermore, an Executive Order in 1985 created the Missouri Head Injury Advisory Council (MHIAC) to plan and recommend methods for preventing TBI and to improve systems for rehabilitation and community services. Working with the Brain Injury Association of Missouri (BIAMO), collaborating agencies, and state policymakers, MHIAC has worked to expand state/federal programs and to better serve individuals with TBI (MOBSHCN, 2004a). Accomplishments since 1985 in the state of Missouri regarding TBI-related policy and initiatives include:

Prior to 2001:

- Legislation passed requiring all hospitals to report TBI creating the Missouri Head and Spinal Cord Injury Registry; and establishing the Missouri Head Injury Advisory Council statutorily (1986). Legislation passed establishing a statewide trauma system regulated by

- the Department of Health (1987). Legislation passed expanding the state Medicaid plan of services to include comprehensive day rehabilitation services for TBI (1988).
- Legislation passed designating the Department of Health as lead agency for TBI (1991).
 - State funding was first appropriated to the Department of Health for two (2) head injury service coordinators for FY'93. By 1997, funding was made available to support eight (8) head injury service coordinators resulting in statewide coverage. In 2002, a ninth head injury service coordinator was added.
 - The Division of Mental Retardation/Developmental Disabilities (MR/DD) designated a case manager in each regional center and habilitation center to be a resource for case managers on TBI issues (1995).
 - The Department of Health received federal grants: Centers for Disease Control and Prevention (CDC) to improve TBI injury surveillance (1989, 1991, and 1997), and implementation grants from Health Resources and Services Administration (HRSA) to improve service delivery (1997-2000; 2000-2001; 2001-2002, and 2002-2003).
 - Governor Carnahan created the Personal Independence Commission (PIC) under Executive Order to monitor Missouri's implementation of Title II of the Americans with Disabilities Act (ADA), with guidance provided by the U.S. Supreme Court in *Olmstead* and subsequent cases. The PIC goals include improving access to all persons with disability, including TBI.

In 2001:

- The Center for Innovations for Special Education (CISE) and the Division of Special Education developed the second module (Identifying Cognitive Strengths and Weaknesses for Students with Traumatic Brain Injury), in a series of training workshops, and held two training workshops for educators. Family members were invited to attend.
- Through funding from the federal TBI grant, the handbook for caregivers, initially developed by the BIA of Missouri and the Missouri Head Injury Advisory Council, was revised to a 5th grade reading level and printed, along with revised family packets by the Missouri Department of Health and Senior Services (DHSS). The handbook was also translated into Spanish and printed. About 1,500 educational packets are distributed annually.
- The DHSS was awarded a one-year TBI Post Demonstration Grant from the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau to develop a single application form and improve data collection among the state agencies.
- The Missouri Department of Social Services, Division of Medical Services (DSS, DMS) received a "Real Choice Systems Change Grant: Systems Change Grants for Community Living" from The Centers for Medicare & Medicaid Services (CMS) to promote the design and delivery of home and community-based services that support people with a disability or long-term illness to live and participate in their communities.
- The Missouri Division of Vocational Rehabilitation (DVR) received an RSA grant "Project

SUCCESS" to develop a single point of entry and an interagency computerized employment intake and planning system in one-stop locations across the state.

- The Missouri Office of Information Technology, Office of Administration, included the TBI project in the E-Government Initiative. This initiative is to develop and implement a state portal and technical infrastructure capable of offering services to businesses and citizens via the Internet. The TBI project is one of five pilot projects that meet the criteria of information sharing and transactions across multiple agencies, thus making it a good candidate for application development utilizing the E-government infrastructure. **Budget reductions have impacted the implementation of OIT plans for this project.**

In 2002:

- The Missouri General Assembly passed legislation establishing a Head Injury Trust Fund to be administered by the Missouri Head Injury Advisory Council for purposes of transition and integration of medical, social, and educational services or activities; outreach; and short-term supports to enable individuals with traumatic head injury and their families to live in the community, including counseling and mentoring the families. The fund is to be created from a \$2 surcharge on all traffic and criminal violations.
- The Missouri Head Injury Advisory Council sponsored its 17th annual conference, "Brain Injury: Promising Practices in Challenging Times," attended by approximately 200 people, including professionals, survivors, families, and state agency representatives. The Director of the Council retired after 17 years, and was replaced by a new Director whose job duties were increased beyond a sole focus on TBI.
- Missouri Protection & Advocacy received a grant from the HRSA MCH Bureau to extend their services to individuals with traumatic brain injury.
- The DHSS Head Injury Manual outlining policies and procedures for both service coordinators and service providers fully incorporated a person-centered approach. More rural providers were recruited (52 to 65). The budget appropriation decreased by \$250,000.
- DHSS was awarded a Post Demonstration Grant to continue activities to streamline access for TBI survivors by development of a systematic early referral from the hospital, exploration of common assessments and further shared data across state agencies.
- Missouri Division of Special Education continued training for educators and families.

In 2003:

- The Missouri Protection and Advocacy provided training in TBI issues for staff. They provided assistance in advocacy for 18 cases and opened one legal case. They have linked with TBI partners in the state, including state agencies, the BIA, and the Head Injury Advisory Council.
- DHSS added the Direct Care Workers Competencies in the Head Injury Provider Manual as requirements for workers providing home and community-based services.
- DHSS developed the Early Referral system and began pilots in five areas of the state.

- The Missouri Head Injury Advisory Council sponsored its 18th annual conference, “Charting Your Course – Full Speed Ahead,” attended by approximately 150 people, including professionals, survivors, families, and state agency representatives.
- The CISE trained 78 educators and family members in TBI on special education issues.
- The Council began development of procedures for use of the Head Injury Trust Fund.
- DHSS continued development of technical infrastructure within the department’s electronic data system, and provided leadership with interagency groups to support the E-Government initiative. Budget restrictions have continued to impact the implementation of plans for this project.
- In 2003, the common information release form, originally developed through the interagency TBI work team, was implemented by all divisions of the Department of Mental Health, DHSS, and Department of Elementary and Secondary Education (DESE, DVR) and placed on the Office of Administration website.

In July 1996, the United States Congress passed the Traumatic Brain Injury Act “to provide for the conduct of expanded studies and the establishment of innovative programs with respect to traumatic brain injury.” The TBI Act of 1996 marked a pivotal developmental step in federal legislation addressing TBI and included four major sections (Corrigan, 2001).

First, it authorized the Centers for Disease Control and Prevention (CDC) to develop projects to prevent and reduce the incidence of TBI. Second, the National Institutes of Health (NIH) was directed to offer grants for basic and applied research on developing new methods for more effective diagnosis, therapies, and a continuum of care. Third, the Center for Medical Rehabilitation and Research at NIH was given the task of conducting a national Consensus Conference on the rehabilitation of individuals with TBI. Fourth and most relevant to current project, the Health Resources and Services Administration (HRSA) in the United States Department of Health and Human Services (DHSS) was given new authority to establish a grant program for states to assist it in addressing the needs of persons with TBI. The resulting State Demonstration Grant Program has made available two categories of grants: planning and implementation (Corrigan, 2001).

*compiled by Christine Rinck, Ph.D, University of Missouri Kansas City Institute for Human Development.

WHAT NEEDS ASSESSMENT HAS BEEN CONDUCTED IN THE PAST?

The Department of Health conducted an assessment of participant needs in August, 1999 as a result of discussions with the Missouri Head Injury Advisory Council and other state government agencies providing services to survivors of traumatic brain injury. The survey was designed to gather information on the satisfaction level and ongoing needs of participants in the Bureau of Special Health Care Needs (BSHCN) Adult Head Injury Program.

Three hundred ninety-five (395) surveys were mailed on July 23, 1999 to people who participated in the BSHCN Head Injury Program during FY99. Of the 395 surveys mailed, 162 responses were received, for a 43.8% response rate.

Participants were asked five (5) questions:

1. How long ago was your brain injury?
2. What services did you receive through the Head Injury Program during the past year?
3. How satisfied with these services were you?
4. My service coordinator was available to me when I needed him/her.
(Agree/disagree)
5. Please tell us how our program could be helpful to you during the coming year. What do you need most for the next year or so?
(Choices were listed)

The following information emerged from the responses:

- Nearly 92% of participants in the BSHCN Adult Head Injury Program were injured more than 12 months ago;
- The services participants most frequently recalled receiving were service coordination, therapy and counseling;
- Some participants were not fully aware of the service coordination involved or the role of the service coordinator. Further analysis will be needed to pinpoint the reasons for this perception;
- More than 70% of respondents reported being “Very satisfied” or “Satisfied most of the time” with the program services;
- Nearly 75% of participants felt that the service coordinator was available when needed;

- Participants listed “help planning realistically for my future” followed by “help getting out and having fun with people that are good for me” most frequently as their needs for the future;
- “Help living on my own” was listed more frequently than “help getting ready for work/school”.

The Adult Head Injury Program began to use this information by revising and implementing a clear philosophy of person-centered planning, along with a benefits package that allows for enhanced flexibility in home and community-based services. The program also helped to clarify the role of head injury service coordinators, and to ensure that program participants were educated about how the service coordinators can assist clients and their families.

E. Scope of the Current Assessment

The current needs assessment project took place over the course of 9 months in 2004. TBI survivors, their family members/guardians, and service providers were interviewed via telephone and focus groups throughout the state of Missouri. Section V provides statistical information and graphs, which specify demographical and geographical information for the samples of individuals contacted and interviewed.

II. Traumatic Brain Injury in Missouri

A. Background & Risk Factors

WHAT IS TRAUMATIC BRAIN INJURY?

TBI is an insult to the brain caused by an impact (e.g., fall or car accident), or internal damage (e.g., gunshot or surgical intervention). A blow or jolt to the head can result in a traumatic brain injury (TBI), which can disrupt the normal function of the brain. More generally, “acquired brain injury” is an injury to the brain, which is not hereditary, congenital, or degenerative that has occurred after birth and includes anoxia, aneurysms, brain infections and strokes. The severity of the injury may range from a mild, brief change in mental status or consciousness, to a severe, extended period of unconsciousness (i.e., 30 minutes or more), prolonged amnesia after the injury, or a penetrating skull injury.

Moreover, any TBI can result in short- and long-term disabilities. Although not always visible, brain injuries may cause enduring physical, emotional, intellectual and social changes for the survivor.

B. TBI Incidence & Prevalence in Missouri

HOW COMMON IS TBI IN THE UNITED STATES AS A WHOLE?

- Over 1.5 million Americans per year will sustain a brain injury resulting in a loss of consciousness but not severe enough to result in long-term hospitalization (CDC, 2004)
- In a typical year, 8 times as many Americans will have a brain injury as will be diagnosed with breast cancer, and 34 persons in the U.S. receive a TBI for every one person with a new diagnosis of HIV/AIDS.
- TBI accounts for an estimated 34% of all injury deaths in the United States (BIAMO, 2004).
- TBI affects males at roughly twice the rate of females, and men have higher mortality rates from TBI than women.
- Among children younger than 14 years, the CDC (2004) estimates 3,000 deaths, 29,000 hospitalizations, and 400,000 emergency visits department per year.
- Individuals between the ages 15 to 24 have the highest risk of TBI with the risk increasing after age 60, and African Americans have the highest death rate from TBI (CDC, 2004).
- Residents in rural areas have a higher rate of both fatal and non-fatal traumatic brain injuries.
- The largest group of TBI survivors is young adults in their prime working years, but many survivors, particularly those with a severe TBI, are unable to return to work

1. WHY IS ACCURATE DATA ON TBI IN MISSOURI IMPORTANT?

Traumatic brain injury is often called a “silent epidemic,” because it has wide prevalence in the population but is often undetected, even by health care personnel. Whether diagnosed or undiagnosed, TBI wreaks havoc on survivors and families. TBI-

related changes in memory, behavior, and emotions often are the most prominent, and the frequent lack of obvious physical signs of TBI cause survivors to be misunderstood and misdiagnosed.

A key reason it is important to provide an accurate estimate of the number of TBI survivors in Missouri is that programs for TBI survivors and families have a mandate to serve this community and must therefore have a general sense of the number of persons who require services. This information is needed so that adequate program staffing, budgets, and planning processes can effectively address the needs of Missourians with TBI.

2. WHAT DO INCIDENCE AND PREVALENCE MEAN?

Incidence refers to the number of persons who sustain a TBI each year, including both those who survive their injuries and injuries resulting in fatalities. Incidence data are the immediate target of most prevention programs such as those that promote bike helmet use, seat belt use, and designated drivers, all of which aim to minimize the number of new TBIs each year.

Prevalence refers to the total number of people living in the population who have TBI. In Missouri, prevalence data would ideally include every person alive in Missouri today who has had a TBI. Prevalence data are affected by factors such as changing annual incidence of TBI, improvements in acute care that lead to increased survival after TBI, and changes in the expected lifespan across the general population and among people with TBI. The greater the survival rate immediately after TBI and the longer the expected lifespan of TBI survivors, the greater the prevalence of TBI among Missouri's population, since more people are living with TBI.

3. WHAT IS THE ESTIMATED RANGE OF TBI INCIDENCE & PREVALENCE?

One of the greatest challenges to TBI program planning is the huge range of incidence and prevalence estimates. When incidence and prevalence are estimated at the high end of actual figures, they may include many individuals who do not require services and whose injury has minimal impact on their lives. When incidence and prevalence are estimated at the low end of actual figures, programs may not have the funding and resources to meet the needs of persons with TBI.

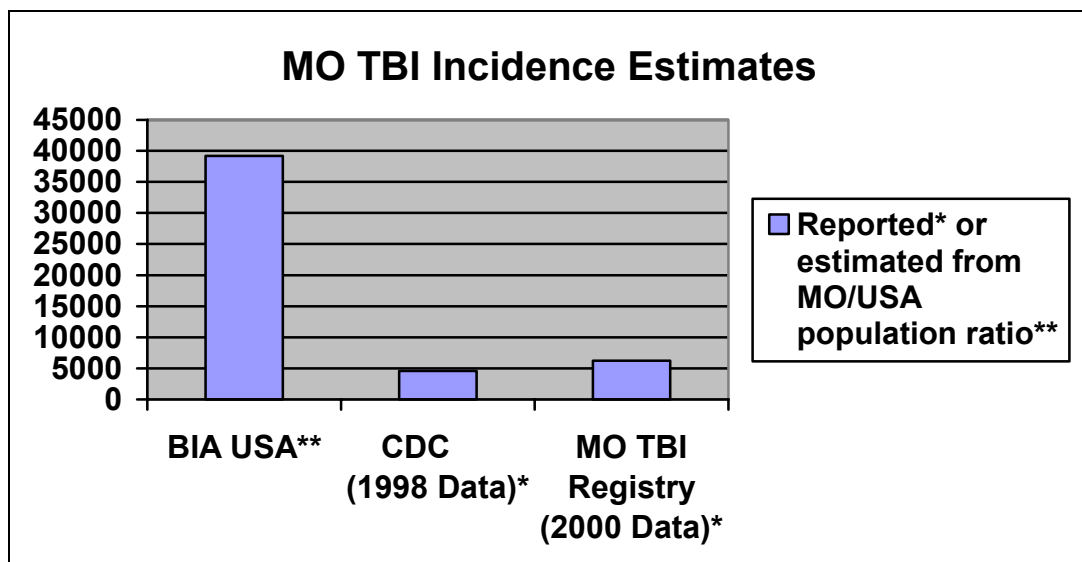
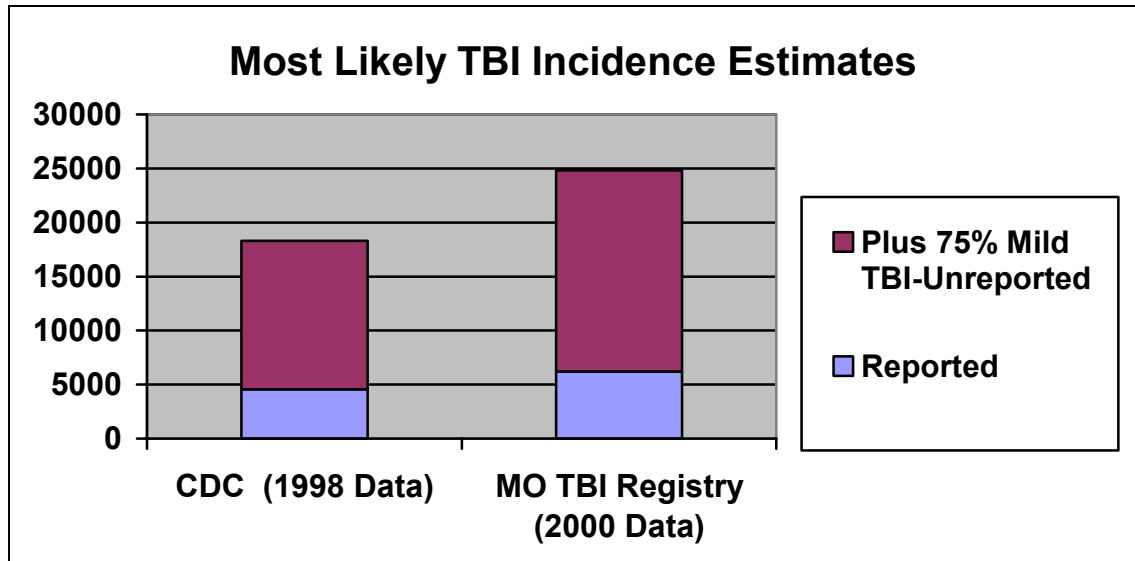
TBI INCIDENCE ESTIMATES VARY WIDELY—WHY?

TBI incidence estimates vary widely, depending on the TBI definition used, the availability of high-quality data from inpatient vs. emergency room settings, and other relevant factors.

WHAT IS THE MOST LIKELY TBI INCIDENCE ESTIMATE FOR MISSOURI?

The CDC acknowledges that 75% of all TBIs are mild TBI cases in which the survivor is usually treated in the emergency room and is not hospitalized. Therefore, a best estimate of incidence should take into account this 75% whose TBIs are usually unreported in sources such as the Missouri Trauma Registry or the Missouri TBI Registry. These Registries underestimate TBI for several reasons: 1) they rely heavily on inpatient cases; 2) they only have access to data from certain trauma centers; 3) they are unable to account for cases in which the evidence of TBI appears after discharge from the acute hospital to rehabilitation or community settings; and 4) they often do not account for TBI secondary to other conditions, such as falls from seizures or strokes. In many of these cases, TBI symptoms, though mild, may require rehabilitation or remedial services, or may prevent a return to full occupational functioning for months or indefinitely. It should be noted that many persons with mild TBI will not require formal services, but because persons with mild TBI symptoms may require short-term services, it is important to count these individuals in estimating incidence for service and program planning purposes.

The best estimates suggest that a total of between 18,300 and 24,832 Missourians will incur a brain injury each year, although only about one quarter of that number will be hospitalized for TBI, and a relatively small proportion will experience lifelong TBI-related disability.



WHAT IS THE MOST LIKELY TBI PREVALENCE ESTIMATE IN MISSOURI?

An estimated 2%, or in 2004, a minimum of 114,089 Missourians have ever been hospitalized for a brain injury from which they have significant continuing disability.

Prevalence estimates include the total number of people in Missouri who are believed to be living with TBI-related disability. The CDC developed a model that takes estimates TBI prevalence by taking into account information on incidence of TBI, injury severity,

and the likelihood of TBI-related disability for given levels of severity. The resulting prevalence estimate reflects the proportion of the population who had ever been hospitalized for TBI and whose TBI resulted in prolonged disability. Therefore, this model necessarily underestimates TBI prevalence, and is heavily weighted toward moderate to severe injury, but despite its limitations it remains the best model to date. Using this framework, CDC estimated based on 1996 data that 5.3 million Americans, or 2% of the U.S. population, were living with TBI-related disability (Thurman et al., 1999). It may be reasonable to assume that Missourians are at comparable risk for TBI as persons from other states (i.e. Missouri's incidence is an estimated 109.9 per 100,000, comparable to many other states with rates ranging from 70.8-113.7 per 100,000; Thurman et al., 1999).

Other estimates of TBI prevalence among general populations are much higher. For example, a recent survey in Kentucky estimated that 12.2% of Kentucky's population had a TBI at some time in their lives, and that nearly 20% of households had a member who had ever had a TBI (Walker et al., 2003). If comparable proportions of Missouri's population had TBI at some time in their lives, the Missouri prevalence would be an estimated 695,947. However, since it is unclear whether Kentucky's definition is comparable to Missouri's definition, and it is also unclear whether Missouri and Kentucky have similar injury rates, this figure does not reflect Missouri's actual TBI prevalence, and certainly would include a high number of persons with mild TBI and no residual impairment.

F. WHAT ARE THE COSTS OF TBI IN MISSOURI?

There are numerous direct and indirect costs associated with TBI in the United States. In particular the CDC (2004) asserted that direct and indirect costs of TBI totaled an estimated \$56.3 billion in the U.S. in 1995. In 1991, survivor costs accounted for \$31.7 billion and fatal brain injuries cost another \$16.6 billion. Furthermore, acute rehabilitation costs for survivors of a severe TBI can average more than \$1,000 per day, with medical costs being typically the highest for those who do not survive (BIAMO, 2004).

III. TBI EFFECTS, PREVENTION AND TREATMENT

A. WHAT ARE THE EFFECTS OF TBI?

The Centers for Disease Control (2004) list the following:

- problems with cognition (e.g., concentration, memory, judgment, and attention)
- movement problems (e.g., strength, coordination, and balance)
- sensation impairment (e.g., touch, vision, etc.)
- changes in emotion and behavior (e.g., instability and impulsivity)
- Long-term effects place an huge emotional and financial burdens on the individual's family
- Health and other service systems are strained in coping with high TBI service costs and life-long service needs

B. WHAT RECOMMENDATIONS ARE AVAILABLE FOR EVIDENCE-BASED PREVENTION OF TBI?

The Centers for Disease Control (2004) have reported success via a number of public health strategies to prevent future TBIs, reduce TBI-related disabilities, and improve outcomes of brain-injured persons. These strategies include the following:

- Increasing helmet use during recreation and sports activities;
- Preventing falls among children and older adults by modifying the environment to reduce fall hazards and the impact of falls; and where possible, reducing medications with side effects that may contribute to falls;
- Enhancing violence-prevention programs designed to decrease the occurrence of self-directed and interpersonal violence;
- Improving use of child safety seats and seat belts and reducing alcohol- and drug-impaired driving;
- Enhancing trauma care surveillance systems and clinical preventive services;
- Improving data collection for TBI incidence;
- Conducting follow-up studies of persons with TBI to assess outcomes and identify service needs;
- Educating persons with TBI about steps to ease recovery and about available services.

C. Other State Intervention Models

The Traumatic Brain Injury Act of 1996 provided the Health Resources and Services Administration (HRSA) in the United States Department of Health and Human Services (DHSS) new authority to establish a grant program for states to assist it in addressing the needs of persons with TBI. The resulting State Demonstration Grant Program made available two categories of grants, planning and implementation. Based upon the recent work of Corrigan (2001), 11 states were reviewed for the basis of comparing their planning and implementation efforts. Overall, the different states were effective in terms of long-range planning, although they employed different strategies in assessing need. For example, Georgia focused on getting TBI survivors, family members and service providers together to prioritize strategies for long term care and identify unmet needs for the survivors and their families.

As Corrigan (2001) points out, return rates for mail surveys in state needs assessments were very low. In some states, as few as 15% of surveys were returned. Mail surveys can also present the problems of confusion about response technique or incomplete responses, leaving the researcher with data that may not be usable or valid. Therefore, telephone or in-person surveys may be more thorough in describing unmet needs of the survivors. Due to differences in data collection and theoretical orientation, the perceived needs and/or solution vary greatly from state to state, making comparison across states difficult. While differing opinions will almost surely continue in terms of how to solve various problems, a system of uniform data collection across states would be beneficial to all involved parties. To at least get all states to look at the same data would be a tremendous first step.

The following table adapted from Corrigan (2001) provides an overview of various states' TBI needs assessment and allows a basis of comparison with this needs assessment of TBI survivors and family members in Missouri. One of the greatest strengths of the current needs assessment project is the sample size and the variety of data sources employed in order to attain a better sense of the needs of the TBI population in Missouri. Moreover, the use of mixed methodologies with telephone interviews, focus groups, and secondary data (i.e., registries), allowed for a deeper, more rich description of the needs of Missouri's TBI survivors and families.

Inter-State TBI Needs Assessments Program Table

Source: adapted from Corrigan (2001)

State	Survivors	Family	Providers	State Agencies	Other
Delaware	Mail/phone surveys from 16 clients of 2 facilities / 2 focus groups of families and survivors	Mail/telephone surveys from 21 families of clients as 2 facilities/ 2 focus groups of families and survivors	Mail surveys from 39 (of 62 sent) service providers	Mail surveys from 22 (of 32 sent) agencies/sub-agencies	Hospital discharge and highway safety data used to describe incidence
Georgia	Mail surveys from 444 (of 2,730 sent) clients of treatments facilities, agencies, or organizations/ 8 Regional town meetings/ Participation in a stakeholders conference	8 Regional town meetings/ Participation in a stakeholders conference	Mail surveys from 724 case managers, social workers and discharge planners throughout the state (response rate not given)/ Participation in a stakeholders conference/ 3 focus groups of 26 survivors, 13 family members, and 14 professionals	Participation in a stakeholders conference	Participation of business executives, elected officials and other interested parties in a stakeholders conference
Illinois	Mail surveys from 895 (of 5,915 sent) clients of rehabilitation programs and support group members/ 3 focus groups of 26 survivors, 13 family members and 14 professionals	3 focus groups of 26 survivors, 13 family members and 14 professionals	3 focus groups of 26 survivors, 13 family members and 14 professionals	-----	-----

Iowa	Telephone surveys from 100 survivors, > 50% 10 yrs post injury/ Follow up surveillance from Dept Public Health on > 400 persons hospitalized for TBI 12-18 months prior/ BIA of Iowa membership survey	BIA of Iowa membership survey	Survey (type not specified) and focus groups/ TBI Rehab Survey	Survey (type not specified) of education, prison, human service and vocational rehab systems	Incidence surveillance data from Dept Public Health/ Data from BIA Iowa Information and Resource System
Mississippi	Mail surveys from 168 (of 415 sent) respondents (sampling method not specified)/ 25 focus groups in 3 locations	Telephone surveys from 80 (of 97 called) respondents (sampling method not specified)/ 21 focus groups in 3 locations	Roundtable discussions with 14 representatives of health and social service agencies/ Mail surveys from 58 (of 176 sent) service providers	Mail surveys from 14 (of 18 sent) state agency/division representatives	-----
Missouri	Telephone surveys from 139 survivors/ 69 focus group members at 7 rural and urban sites.	Telephone surveys from 106 family members / 39 focus group members in 7 rural and urban sites.	Telephone surveys from 183 service providers / 49 focus group members in 7 rural and urban sites.	Telephone surveys from 45 program administrators in 6 state regions (rural and urban agencies).	Incidence surveillance data from DHSS, ER audits, Acute rehabilitation hospital studies, Missouri Model Brain Injury System data, jail and prison behavioral health service provider interviews, CDC documents
Oklahoma	Mails surveys from 269 (of 1,181 sent) survivors and family members randomly sampled from the TBI Surveillance System and 59 members of support groups (47%	Mails surveys and telephone surveys from > 200 providers and agencies/ Focus group with 12 community health professionals	Mails surveys from 68 (of 68 sent) county health departments	Incidence surveillance data from the Injury Prevention Service, Dept of Health	-----

Oklahoma (cont.)	of respondents were survivors)/ Telephone interviews with 80 survivors and family members/ Focus group with 14 TBI support group members				
Oregon	Mails surveys (population and sample not described)/ Town meetings (60 attending 14 meetings)	Mails surveys (population and sample not described)/ Town meetings (27 attending 14 meetings)	Mail surveys from 115 respondents/ Resource assessment survey of 50 providers and state agencies	Resource assessment survey of 50 providers and state agencies	Focus Group with Advisory Board members
South Carolina	Mail surveys from current clients in Department of Disabilities and Special Needs services (78 of 349 returned) and persons identified by TBI support group (0 of 125 returned)/ Focus group	Mail surveys from family members of Dept of Disabilities and Special Needs clients (71 of 250 returned) and families identified by TBI support group (0 of 125 returned)/ Focus group	Mails surveys from 12 providers (of 24 sent)/ Focus groups (2)	Nominal group process with agency/ Interviews with “priority” agencies/ Focus Groups (2) with Department of Disabilities and Special Needs service coordinators/	-----
Texas	Mail surveys from 124 BIA members or public meeting attendees (1,000 mailed)	Mail surveys from 84 BIA members or public meeting attendees (1,000 mailed)	Mail surveys from 100 public agencies (1,000 mailed)	Mail surveys from 14 public agencies (1,000 mailed)	Policy Analysis of Health and Human Service delivery systems
West Virginia	Mail surveys from 135 (of estimated 650 sent) to BIA clients in WV	Mail surveys from 35 (of 56 selected) from clients in EMS, trauma center and surveillance registries	Mail surveys from 82 service providers (of 386 sent) selected by BIA-WV and Vocational Rehabilitation	-----	-----

West Virginia (cont.)			Services		
Wisconsin	Mail surveys from 504 (of 1,972) BIA members and clients of service providers, ILCs and state DD services	Mail surveys from 23 (of 46) TBI and DD services; community provider retreat with 120 participants	Mail surveys from 22 (of 66 sent) bureaus and departments of state government	-----	-----

The following information regards funding in relation to states' respective populations. This information provides a basis of comparison for the amounts contributed and means of attaining TBI funding via trust funds and Medicaid waivers. As can be seen from the information provided, Missouri's Trust fund source is primarily from traffic citations (\$2) (MOBSHCN, 2004b). Other states employ similar sources of funding based upon surcharges, traffic fines, DUIs, and other moving violations.

MODEL TBI TRUST FUNDS FROM OTHER STATES

Source: Missouri Bureau of Special Health Care Needs (2004b)

EXAMPLES OF SOURCES OF CONTRIBUTIONS TO FUND

Colorado	Population in 2003: Trust fund source:	4,550,688 \$10 all traffic fines, \$15 DUI Annual contributions: \$2.5 million
Arizona	Population in 2003: Trust fund source:	5,130,632 surcharges - civil, criminal, fines and forfeitures Annual contributions: \$1.8 to 2.4 million
Mississippi	Population in 2003: Trust fund source:	2,844,650 \$25 surcharge DUI, \$4 all other moving violations Annual contributions: \$2.5 million
New Jersey	Population in 2003: Trust fund source:	8,414,350 Surcharge on all motor vehicle registrations Annual contributions: \$3.4 million

Florida	Population in 2003:	15,982,378
	Trust fund source:	A percentage of fees levied from traffic fines, surcharges on driving and boating DUI and temporary license tags
		Annual contributions: \$15 million
Missouri	Population in 2003:	5,704,484
	Trust fund source:	\$2 all citations
		Annual contributions: \$852,400

Many states offer TBI services under Medicaid waivers, and states vary on the number of services per waiver, with 29 states currently having a Medicaid waiver for TBI-related services (MOBSHCN, 2004b). Moreover, there is comparative data that contrasts the number of states that utilize TBI waivers for the same or similar services provided in the state of Missouri via DHSS.

MODEL TBI MEDICAID WAIVER PROGRAMS

Source: Missouri Bureau of Special Health Care Needs (2004b)

INCREASING STATE DOLLARS THROUGH MEDICAID WAIVER

27 States currently provide at least one type of service with a TBI Medicaid Waiver:

- 4 states provide 1 – 10 services with TBI waiver: Mississippi, Nevada, New York, and Utah
- 4 states provide 11 – 15 services with TBI waiver: Delaware, Iowa, Nebraska, and Vermont
- 8 states provide 16 – 20 services with TBI waiver: Illinois, Indiana, Kentucky, Massachusetts, New Hampshire, North Dakota, South Carolina, and Wyoming
- 7 states provide 21 – 25 services with TBI waiver: Colorado, Connecticut, Florida, Idaho, Iowa, New Jersey, and Wisconsin
- Minnesota provides 27 services with TBI waiver
- Pennsylvania provides 33 services with TBI waiver

** In 2004 Montana and Maryland added Medicaid waiver to their TBI funding.*

OTHER STATES WAIVER PROGRAMS OF INTEREST BY TITLE

Colorado – Acquired Brain Injury
 Maine – Adults with Disabilities or Physical Disability Waiver
 Georgia – Individual Care Waiver
 Michigan – Medicaid Choice Waiver
 Kentucky – Acquired Brain Injury
 Washington – Aging and Disability Waiver

**Comparative Chart of Services provided through
Missouri Department of Health & Senior Services
Source: Missouri Bureau of Special Health Care Needs (2004b)**

SERVICE Provided in Missouri Adult Head Injury Program	Number of States Utilizing TBI Waivers for Same or Similar Services
Neuropsychological Evaluation & Consultation	18
Occupational Therapy	14
Physical Therapy	14
Pre-Vocational / Pre-Employment Training	16
Speech/Language Therapy	15
Supported Employment – Long Term Follow-up	16
Transitional Home & Community Support	19 – Independent Living Skills Training 6 – Assisted Living
Transportation	18
Comprehensive Day Program	9 – Day Services, Medical 13 – Day Services, Social
Counseling	21
Recreation (Recreation Services Discontinued July 1, 2003)	8 – Recreation 19 - Respite

C. Missouri Model

Missouri's TBI service delivery system is comprised of multiple partnerships between collaborating agencies and state policymakers. The key state agencies and bodies that have been involved in the Missouri Model of TBI Service Delivery are the following:

- Missouri Head Injury Advisory Council (MHIAC)
- Missouri Model Brain Injury System (MOMBIS & University of Missouri)
- Department of Health and Senior Services (DHSS)
- Bureau of Special Health Care Needs (BSHCN)
- TBI Interagency Task Force
- Adult Head Injury Service in DHSS
- Department of Social Services (DSS)
- Division of Vocational Rehabilitation (DVR)
- Division of Medical Services (DMS)
- Brain Injury Association of Missouri (BIAMO)
- Center for Head Injury Services

The DHSS Head Injury Program has a rapidly growing waiting list for its services in support of community (rather than institutional) living. Despite this need, Missouri has no TBI Medicaid Waiver program, even though Medicaid Waiver programs can draw

federal dollars into Missouri for head injury Services at a 60/30 match, leveraging Missouri's investment dollars. Other states have used targeted surcharges and fees to build their TBI trust funds and decrease the use the state's General Revenue for operations.

IV. Existing Missouri TBI Services Delivery System

A. Resource Capacity Assessment

The Bureau of Special Health Care Needs in the Missouri Department of Health and Senior Services (MOBSHCN, 2004a) reported that 6,208 Missourians experienced a TBI in the year 2000. Nearly half 45% were injured as a result of motor vehicle crashes. More than half 62% of those who sustained a traumatic brain injury were males. In at least 11% of injuries, alcohol use was known to have occurred.

The number of individuals served by the DHSS Special Health Care Needs' Head Injury Service increased from 243 in 1997 to 491 in 2002. The number served for 2003 is 403, reflecting a smaller budget, and approximately 80% of those served were Caucasian.

B. TBI Partnerships and Current Initiatives

According to documentation from the Missouri Bureau of Special Health Care Needs (MOBSHCN, 2004a), the Department of Health and Senior Services (DHSS) began contracting for services for individuals with TBI and their families as the result of state appropriation for Fiscal Year 1986. Funding has increased through the years, not only for rehabilitation, in-home support, supported employment, and other services, but also for service coordination. However, in 2002 and 2003, core budget cuts were made due to budget shortfalls.

The Adult Head Injury Service is funded by both General Revenue and Federal funds, collected from DSS, and dispersed by DMS through Interagency Agreements designed to maximize General Revenue Funds. In 1991, legislation passed designating the Department of Health (now Department of Health and Senior Services) as the lead state agency for adults. In 1998, the Bureau of Special Health Care Needs (BSHCN) was also deemed the lead agency for children and youth. The Head Injury Service is

administratively housed in the DHSS, Division of Community Health Bureau of Special Health Care Needs. The Missouri Head Injury Advisory Council (MHIAC), located in the DHSS, is the advisory board to the department and all relevant agencies on head injury. State General Revenue funds \$1,448,498 for head injury service coordination, rehabilitation, and supports/services (MOBSHCN, 2004a).

MOBSCHN (2004a) notes that the number of providers has expanded from seven head injury providers in 1986 to 65 providers throughout the state in 2003. Growth in rural areas' provider bases has been achieved through a focus on recruitment in those areas by the Head Injury staff. A Service Manager supervises nine regional service coordinators. DHSS contracts with local public health agencies and the University of Missouri-Mount Vernon for service coordination. A Policy and Procedure Manual available on the DHSS website delineates the program activities. Since the first TBI Implementation Grant, training has been provided to over 300 service coordinators/case managers across state and local agencies, including Missouri Protection and Advocacy Staff, on TBI issues and interagency person-centered planning.

DHSS also convened the TBI Interagency Task Force to enhance the working relationship of other state agencies with the Head Injury Service. Some of the state agency representatives are also members of the council or have been appointed by their directors, who serve on MHIAC, to represent their agencies on this working committee. This committee worked on how to implement recommendations of the council, other policymakers, and consumers. Through the work of this committee, ideas were generated for development of shared information and referral, as well as implementation of a common interagency release form. The director of MHIAC has actively participated with the DHSS injury control committee, as injury prevention is a major activity in the council's strategic plan (MOBSHCN, 2004a).

MHIAC has been a major impetus for interagency cooperation. Members of the Council, who were state legislators, introduced and passed legislation creating the registry, Council, head injury program, trust fund, and funding for services. Membership on the Council includes state agency staff, individuals with TBI, family members, legislators, and professionals.

The Council has also sponsored 18 statewide annual conferences, one statewide

prevention conference, statewide workshops on housing and on supported employment, and has sponsored three different sets of regional workshops. The Council maintains reference materials, a website linking to all TBI state resources, and exhibits at conferences sponsored by the Division of Special Education, Health Educators, Developmental Disabilities, etc. Council staff and some members serve on several committees and task forces, such as the MO Transitional Advisory Panel, Home of Your Own, and Olmstead Stakeholders group. Some members are also Board members of the Brain Injury Association of Missouri. Some of the activities further listed by MOBSCHN (2004a) that have been conducted by the Council are the following:

Activities Conducted by MHIAC in Support of Program
Source: Missouri Bureau of Special Health Care Needs (2004a)

Year	Activity
1986	Survey of Missourians with severe head injury served by state agencies and issued report
1986	Published 1 st Annual Report/State Plan
1986	Defined head injury for purposes of registry/services; and type/range of services needed—issued report
1986	Developed legislation establishing head and spinal cord injury registry; council statutorily
1988	Developed statewide poll to determine awareness and knowledge of public with regard to head injury conducted by University of MO, Bureau of Media Research
1988, 1991	Council sponsored public hearings to obtain consumer input for service priorities.
1991	Initiated legislation establishing services in the Department of Health
1994/1998	Task Forces on Pediatric Head Injury/Children and Youth: Issued Reports & Recommendations
1995	Recommended case manager in each regional and habilitation center be designated as resource staff for TBI and assisted with in-service training.
1997	Recommended caregivers guide be developed, and produced in partnership with

2001	BIA; and reprinted throughout years. Family packet of materials produced and made available to hospitals and rehabilitation centers (and others) for families developed by council, DOH, and BIA with funding from DOH in 1997 and updated in 2001.
1998	Recommended Bureau of Special Health Care Needs be lead agency for children with TBI
1998, 2000, 2001	Advocated that the Department of Elementary and Secondary Education develop manual for educators, training, and capacity for offering consultative services to local school districts. DESE contracted with Center for Innovations in Special Education to produce manual for educators on TBI, and began training in 2000. Continued to assist with ongoing evaluations and revisions to curriculum.
2000	Developed playground safety project in cooperation with Central Mo. State Univ. Safety Center, Department of Health, and 4-H Clubs
2001- present	Continued funding of Support Partner program developed with HRSA funding by the DHSS.
2001- present	Actively supported legislation for a primary seat belt law, and continued to support the motorcycle helmet law.

Moreover, MOBSHCN (2004a) reports that Missouri has had a number of federal grants, some of which are outlined below:

Selected Recent Federal Grants
Source: Missouri Bureau of Special Health Care Needs (2004a)

Grant	Year	Description
NIDRR	1997	University of Missouri-Columbia: To establish a model system of care for persons with TBI and participate in a national TBI database
Center for Disease Control and Prevention	1989	Dept. of Health: To develop injury control capacity.
	1991	Dept. of Health: To develop program/strategies to prevent primary and secondary disabilities
	1997	Dept. of Health: To improve injury surveillance
HRSA	1997-2000	Dept. of Health: Training for case managers-person centered planning; Support Partner program; Development of webpage TBI-MO.; Resources for TBI; develop evaluation/outcomes for head injury services
NIDRR	1997	(UMC) Switzer award to improve neuropsychology service access for persons with TBI in underserved communities.

NIDRR	1998-2001	(UMC) Field Initiated proposal to conduct capacity-building for behavioral health services for persons with TBI in underserved communities.
HRSA	2000-2001	Dept. of Health and Senior Services: Minority Outreach, competencies for direct care providers, to sustain Missouri Support Partners
HRSA	2001-2002	Dept. of Health and Senior Services: Interagency collaboration to develop a more streamlined state system.
CMS	2001-2004	Dept. of Social Services, Division of Medical Services. Real Choices/Ticket to Work: To provide individuals with choices in their lives and Medicaid services for individuals who work. (2 grants)
HRSA	2001-2004	Protection and Advocacy: To increase MO P&A's responsiveness to TBI issues and engage in outreach activities with/to the brain injury community to ensure culturally competent legal-based advocacy services for individuals with TBI.
NIDRR	2002-2005	(UMC-Schopp). Field Initiated project to develop an information management system for persons with TBI and other disabilities.
RSA	2001-2006	DVR (Project Success): To streamline and improve the process for persons seeking employment in a one stop location by providing real time data sharing electronically.

V. Current Missouri Needs Assessment Methods

A. Interviews of Survivors, Families/Guardians, and Service Providers

1. WHAT SURVEY METHODS WERE USED?

The goal of this project was to identify key barriers to effective service delivery for persons with TBI and their family members. Surveys were based upon previous TBI needs assessments projects conducted in Maryland and Iowa. After pilot-testing the surveys, the team adapted separate surveys for adult survivors, child survivors, family members, and service providers. The surveys were administered in person or by phone, and since the surveys relied on open-ended questions, they took between 30 and 90 minutes to administer. Additional tailored surveys were developed for special subgroups, such as persons providing services in corrections facilities and agency administrators.

The research team recruited a total of 5 research assistants to conduct the statewide telephone surveys during the course of the project. These interviewers were hired on schedules designed to ensure smooth coverage throughout the survey period. The interviewers were trained in basic TBI issues, conducting professional telephone interviews, and confidentiality issues.

2. WHO PARTICIPATED IN THE SURVEYS?

Referring to the figure below, one can see the research team conducted a total of **428 interviews**. The total number of surveys included the following:

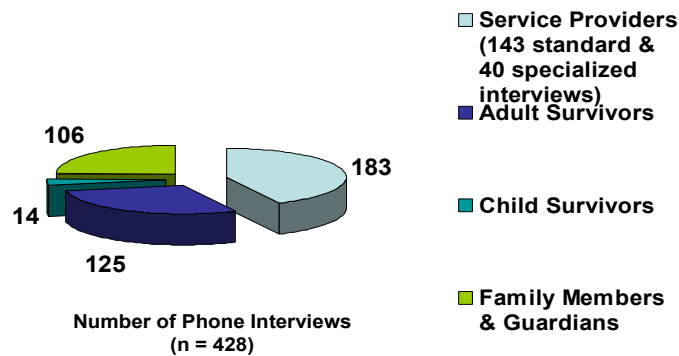
- **183 service providers,**
- **125 adult survivors,**
- **14 child survivors,**
- **106 family members.**

To achieve this sample, the team attempted contact with a total of **674 individuals**. The total number of contacts included the following:

- **296 service providers,**
- **156 adult survivors,**
- **35 child survivors,**
- **148 family members.**

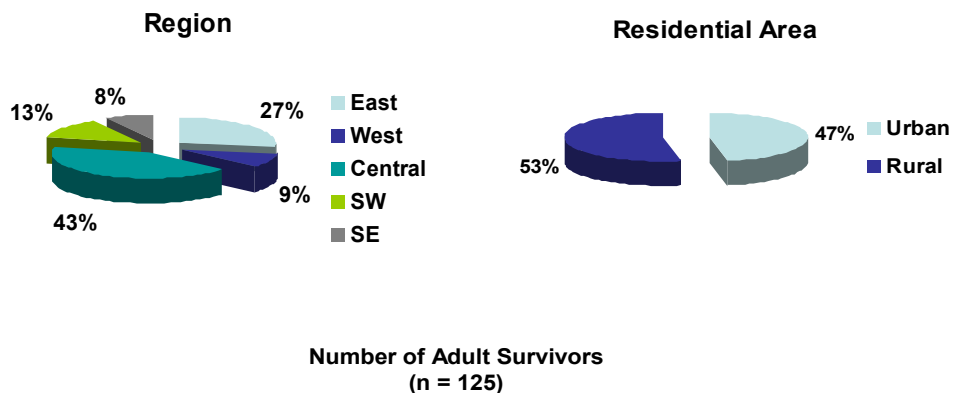
The primary reason surveys were not completed was inability to schedule a time for the survey. Overall, these data suggest an outstanding participation rate, particularly among adult TBI survivors and family members.

MO TBI Needs Assessment Number & Type of Interviews

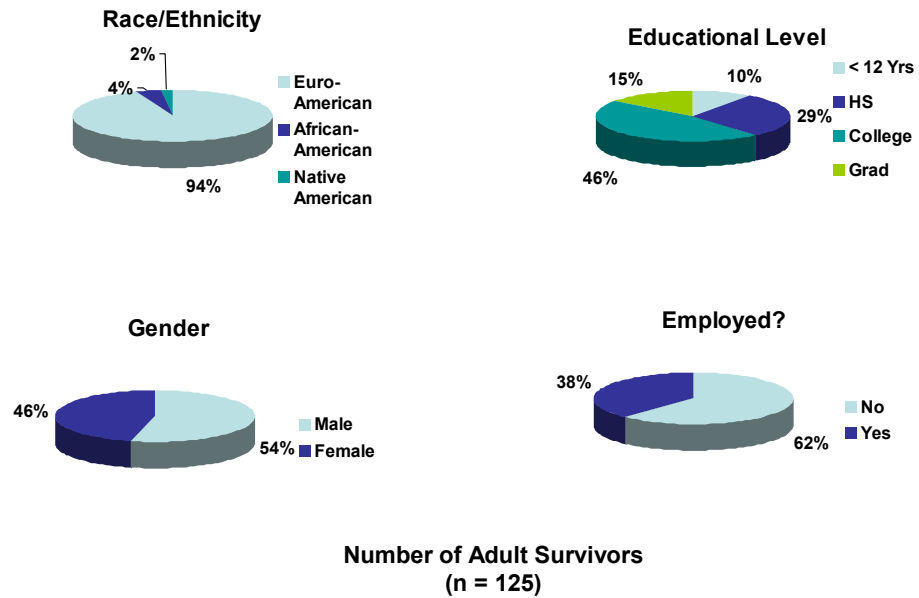


The figures below reveal that the survivors and family members/guardians included individuals with a variety of causes for TBI who live in urban, suburban, and rural areas. Interviewees were contacted throughout Missouri including private, public and non-profit organizations in Eastern, Western, Central, Southwestern and Southeastern regions of Missouri.

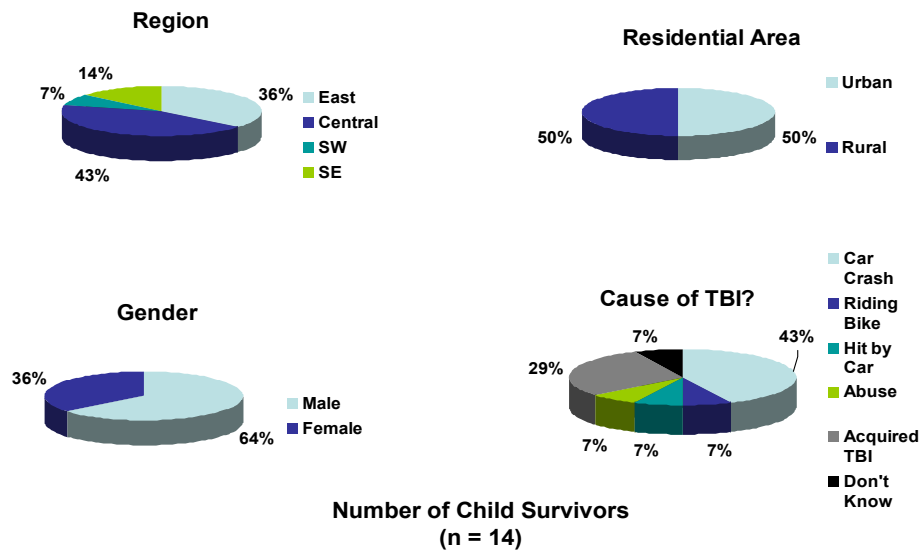
Geographic Information for Adult TBI Survivors in Missouri

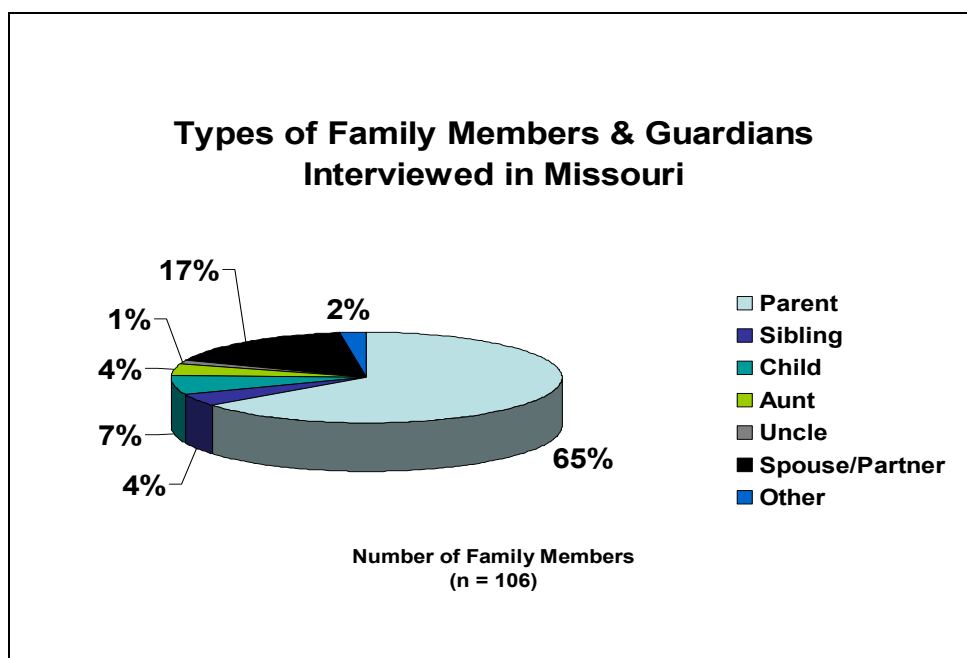


Demographic Information for Adult TBI Survivors in Missouri



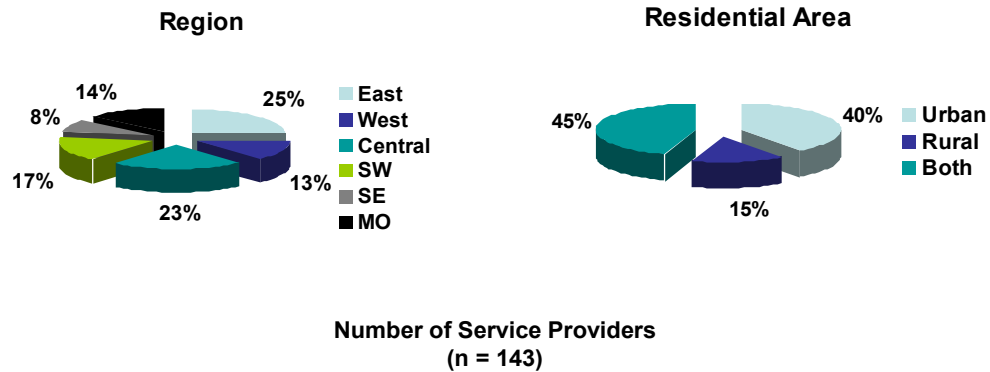
Descriptive Information for Child TBI Survivors in Missouri



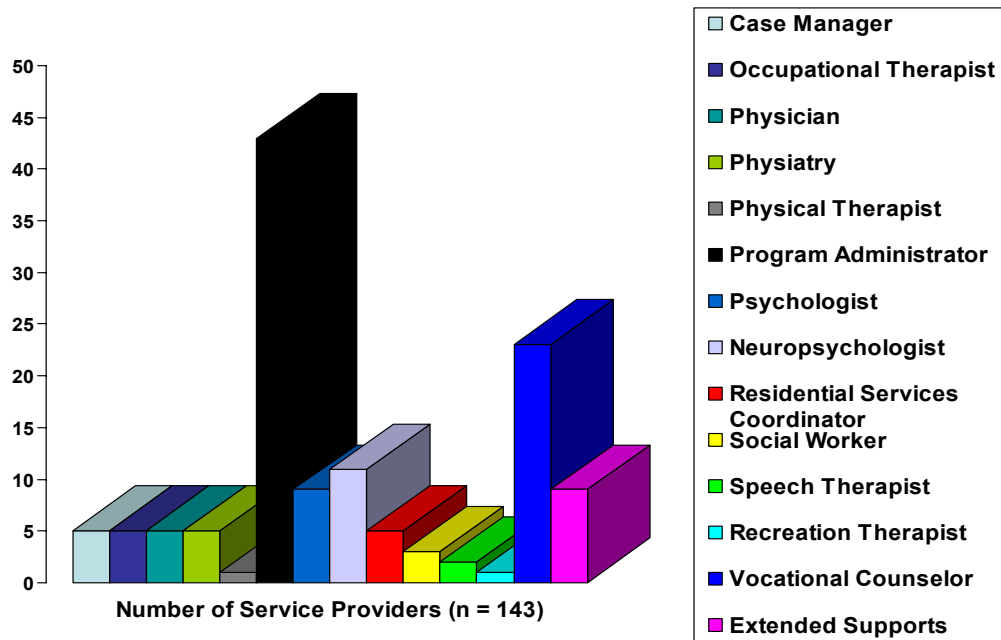


Looking at the figures below, one can see the providers were a heterogeneous group of 183 psychiatrists, neurologists, neuropsychologists, psychologists, social workers, rehabilitation residents/fellows/ interns, program administrators, occupational therapists, physical therapists, speech therapists, vocational rehabilitation counselors, Independent Living Center (ILC) staff members and community volunteers. Note that the following graphics include data only from the 143 standard provider interviews, excluding data from the 40 customized interviews for provider subgroups, since not all customized interviews contained all data elements.

Geographic Information for TBI Service Providers in Missouri



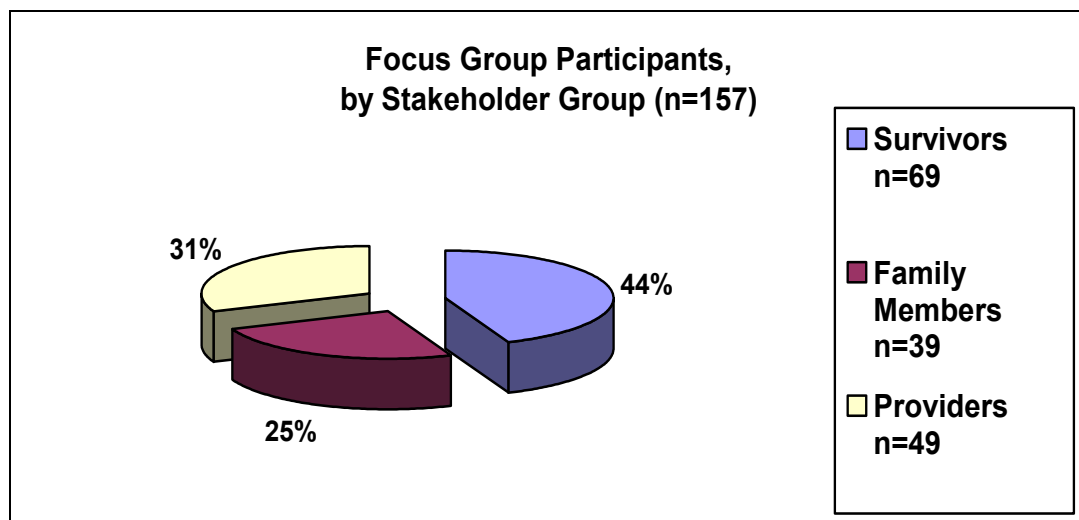
TBI Service Providers Interviewed for Missouri Needs Assessment



B. Focus Groups to Identify Stakeholder Perspectives & Service Gaps

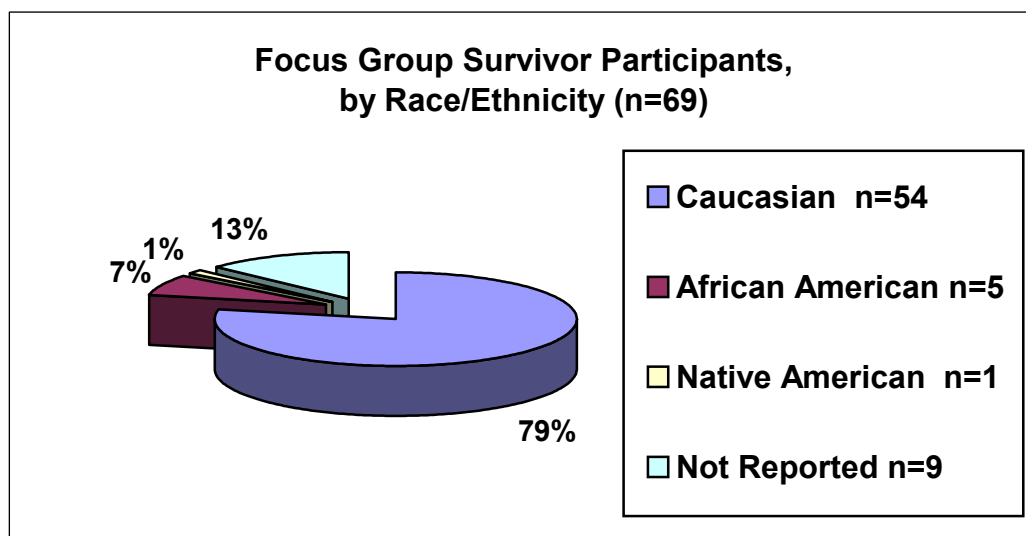
One of the primary goals of this project was to identify the main gaps that exist in the service delivery systems for persons with TBI, and to propose possible solutions to these problems. The project team facilitated focus groups with TBI survivors, family members/guardians, and service providers to discuss gaps, identify remedies, and make a realistic assessment of priorities. In doing so, the project worked to ensure that racial/ethnic and geographic diversity were reflected in the findings, and that the views of various stakeholder groups were represented. Referring to the figure below, one can see the total number of individuals involved in the focus groups was **157 participants**. The total number of focus group participants included the following:

- **49 service providers,**
- **69 survivors,**
- **39 family members.**

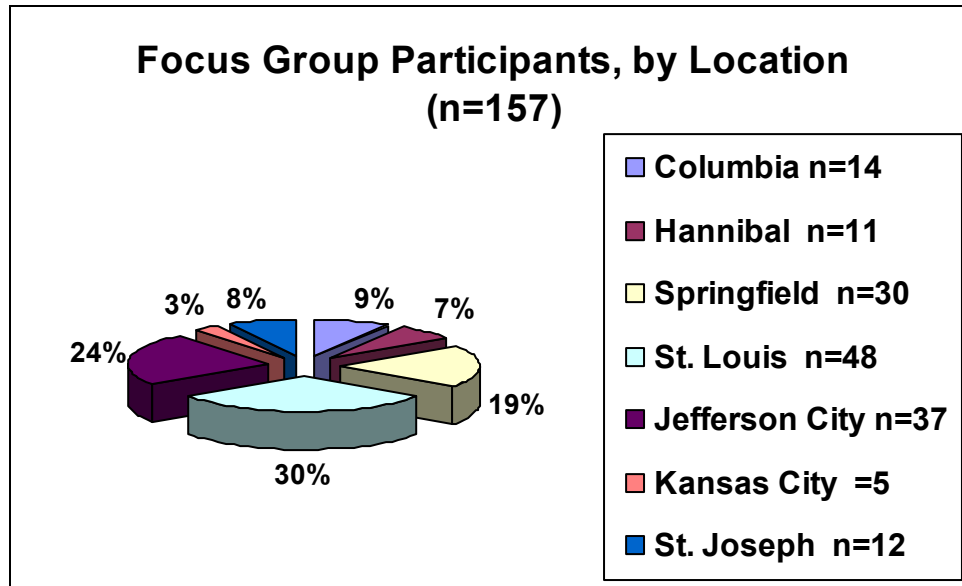


1. WHO PARTICIPATED IN THE FOCUS GROUPS?

Individuals from a range of backgrounds and experiences with TBI were interviewed in a statewide series of focus groups. These focus groups were designed to capture perspectives from various stakeholder groups, with their concerns primarily reflecting their personal or professional experiences with TBI (e.g., individuals with TBI, family members, administrators, physicians, rehabilitation therapists, psychologists, VR counsellors, case managers, TBI service coordinators, etc.). Several groups were targeted at certain subgroups of knowledgeable individuals, such as TBI service coordinators, Independent Living Center administrators, minority group family members of TBI survivors, and TBI survivors from both rural and urban environments.



Individuals from all regions of the state participated in this process, with focus groups conducted in St. Louis, Kansas City, St. Joseph, Springfield, Jefferson City, Columbia and Hannibal. Some urban locations had more than one focus group. Because survivors were predominantly Caucasian, two of the groups were especially targeted at eliciting information from minority group members (especially African Americans), including a predominantly minority survivors' focus group and a family members' focus group with minority group representation.



2. HOW DID THE FOCUS GROUPS WORK?

Participants were primarily asked to state their concerns regarding any perceived lack of specific services for persons with TBI in Missouri, and to provide suggestions for ways to improve any deficiencies. However, it is important to note that they also stated their satisfaction with many services throughout the state, and acknowledged that many agencies and service providers were doing their best given limitations in the systems. Given that this assessment was focused on identifying gaps in service delivery systems, this report focuses weaknesses and deficiencies in the systems, with the hope that readers will realize this information is conveyed in the spirit of improving the lives of individuals with TBI.

3. HOW ARE THE FOCUS GROUP FINDINGS ORGANIZED?

Although a very wide range of concerns and solutions was offered, in general there was consensus regarding the main areas in which problems exist. In order to present this information in as a concise and useful format as possible, the concerns reported have been categorized into the following areas of general concern. After each problem area is discussed, possible solutions to these problem areas are offered. Of course these are not the only solutions available, but they represent a starting point for action plans based on the opinions of knowledgeable stakeholders.

C. Data Analyses

1. Telephone Interview Data

With the assistance of the University of Missouri's Biostatistics Department, the research team employed descriptive statistical analyses to analyze the telephone interview data from TBI survivors, family members/guardians, and service providers. After quantifying the interview data using expert clinical judgment and allowing the emergence of themes from the interviews, the research team provided output for frequencies of responses on the survey questions. The research team also created output for means, medians, and modes to analyze data variation within and between the subgroups.

2. Focus Group Data

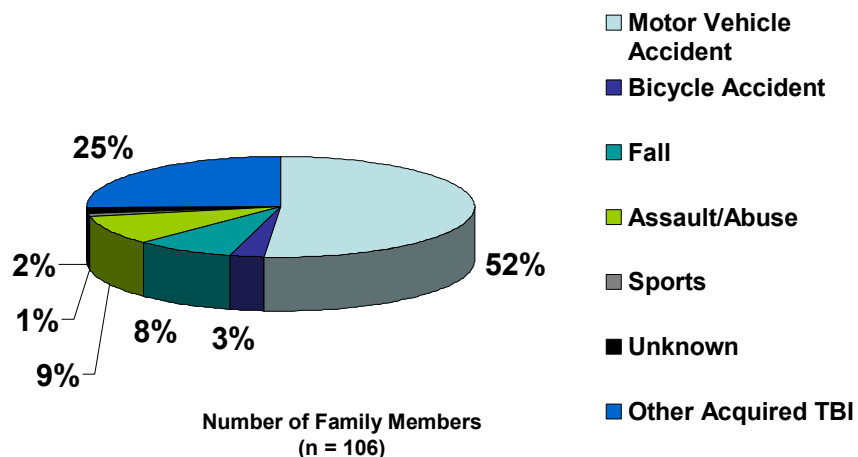
The research team employed a qualitative analysis to categorize the focus group data into relevant themes, which emerged across the course of group interviews with TBI survivors, family members/guardians, and service providers. The categories served to create taxonomies of the focus group data. The research team also provided descriptive information regarding the number of focus groups, participants, and geographical location.

VI. WHAT DID THE SURVEYS AND FOCUS GROUPS FIND?

A. Interviews of Survivors, Families, and Service Providers

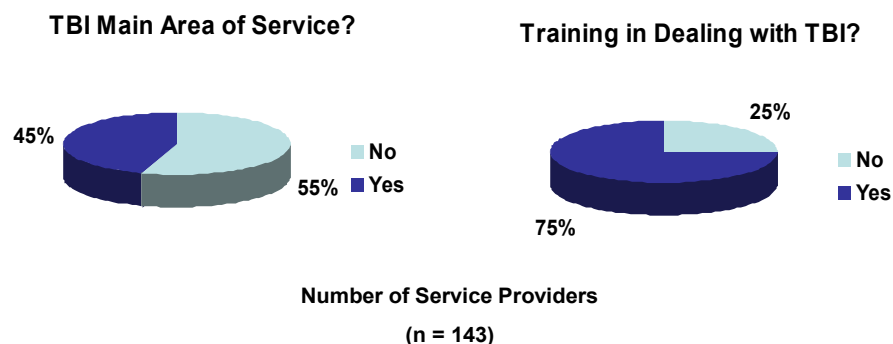
Looking at the figure below, one can see that family members and guardians of TBI survivors indicate that motor vehicle accidents (MVAs) were the most frequent cause of their family member's TBI. Bicycle accidents accounted for another large proportion of TBIs, with a smaller proportion due to falls, assault/ abuse, sports, unknown causes and other acquired TBIs. These data are in general accord with national TBI samples, indicating that this sample is generally representative of the TBI population with respect to cause of injury.

Causes of Survivors' TBI Listed by Family Members & Guardians in Missouri

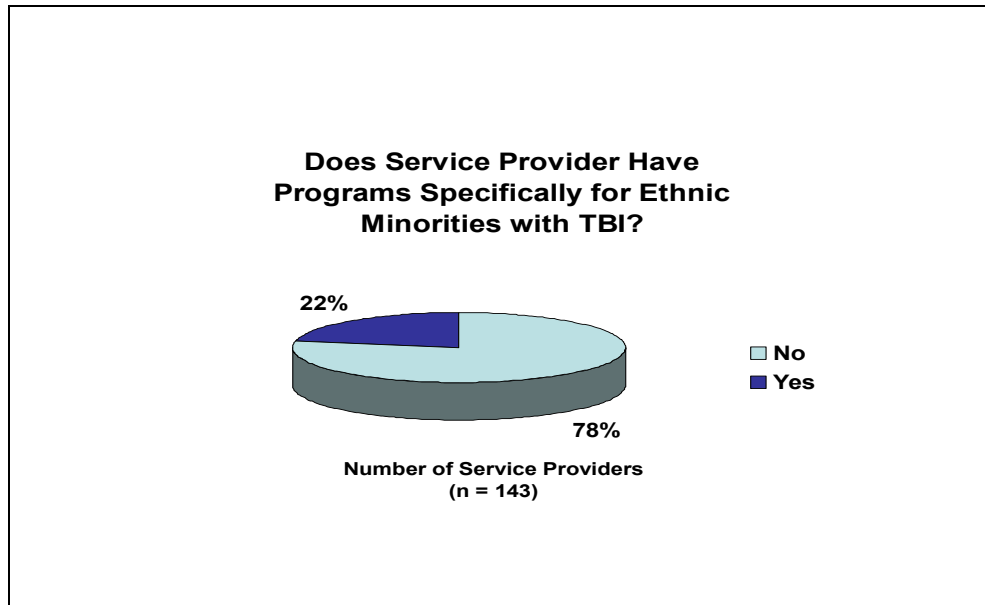


TBI service providers noted several important aspects about their services. A majority of service providers interviewed for this project did not see TBI as their main area of service, but most had some formal and/or informal training in TBI.

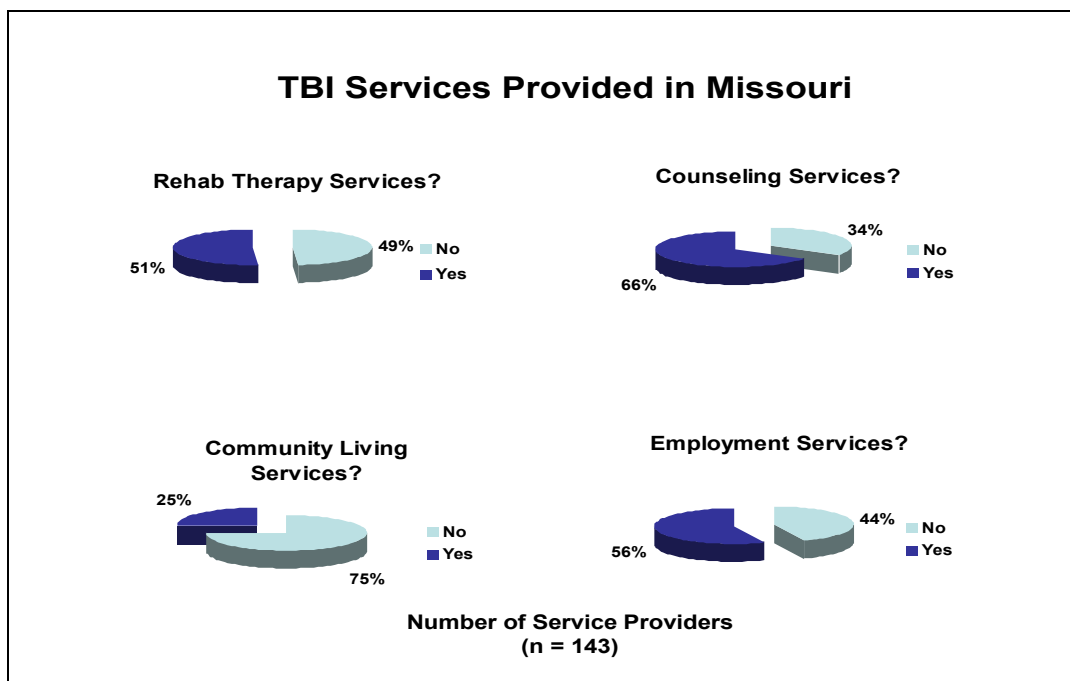
Capacity of TBI Service Providers in Missouri



Not surprisingly, most TBI service providers interviewed revealed that they do not have programs specifically for ethnic minority group members with TBI.



A majority of the service providers interviewed stated that their practice or agency provided rehabilitation therapy, counseling and employment services, but a majority noted that they did not offer community living services.



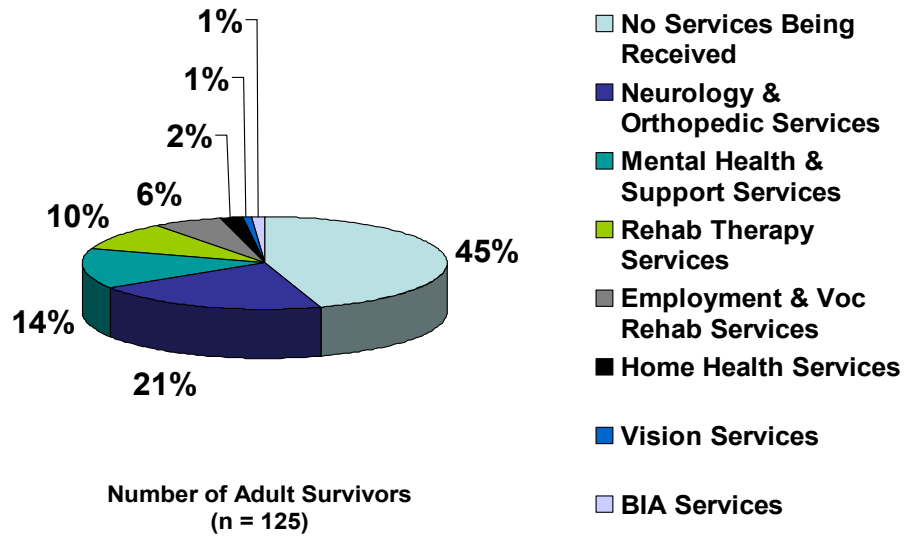
The Brain Injury Association of Missouri was helpful in sharing its mailing list with this project. However, because the list was not sub-coded by category (e.g., survivor, family, professional, etc.), the list could only be used to target persons with an interest in brain injury, rather than targeting by subgroup. The list was also out of date, with an average of 5 contact attempts per completed contact from that list. To supplement this list, the team secured other sources of TBI survivor information, such as going through statewide support groups, inpatient and outpatient client lists, children's service providers, and varied sources such as the Center for Head Injury Services in St. Louis and snowball sampling from previous interviewees. These strategies ensured that we sampled a broad range of persons with TBI, rather than single-source, more homogeneous contacts.

The research team worked with the MO Department of Health and Senior Services (DHSS), the Brain Injury Association of MO (BIAMO), the MO Statewide Independent Living Council (SILC) and the MO Division of Vocational Rehabilitation (DVR) as part of the process of examining/evaluating data sources to develop survey call lists for brain injury survivors and their families throughout Missouri.

Interview respondents were asked open-ended questions to elicit the primary concerns they experience about services and supports for persons with TBI. To minimize the likelihood of "leading questions," survivors were not asked to rate *whether* each response category was a concern, but were asked *what* their primary concerns were.

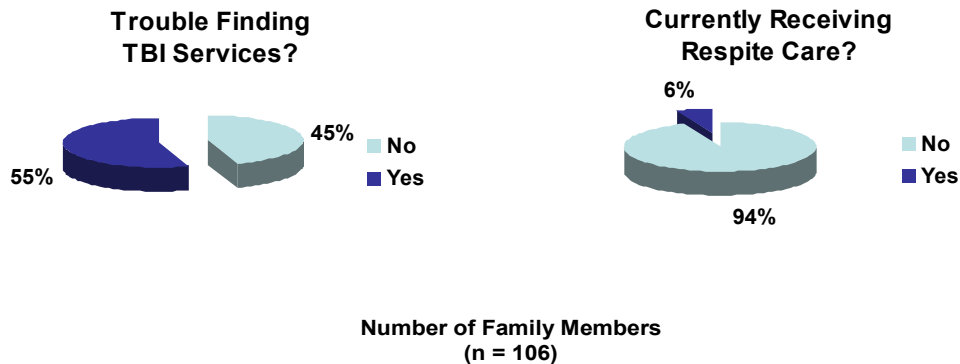
Adult survivors provided a listing of the services that they are currently receiving. The majority of adult TBI survivors reported that they are not currently receiving services. Neurology and Orthopedic, Mental Health and Support, Rehab Therapy, and Employment and Vocational Rehabilitation services are listed as the most frequent categories of services being received by adult TBI survivors in the report sample. Home health, vision, and Brain Injury Association support were listed as least frequently used by the adult survivors in this sample, indicating that many survivors are not connected with the existing brain injury support structure.

Services Currently Received by TBI Survivors in Missouri

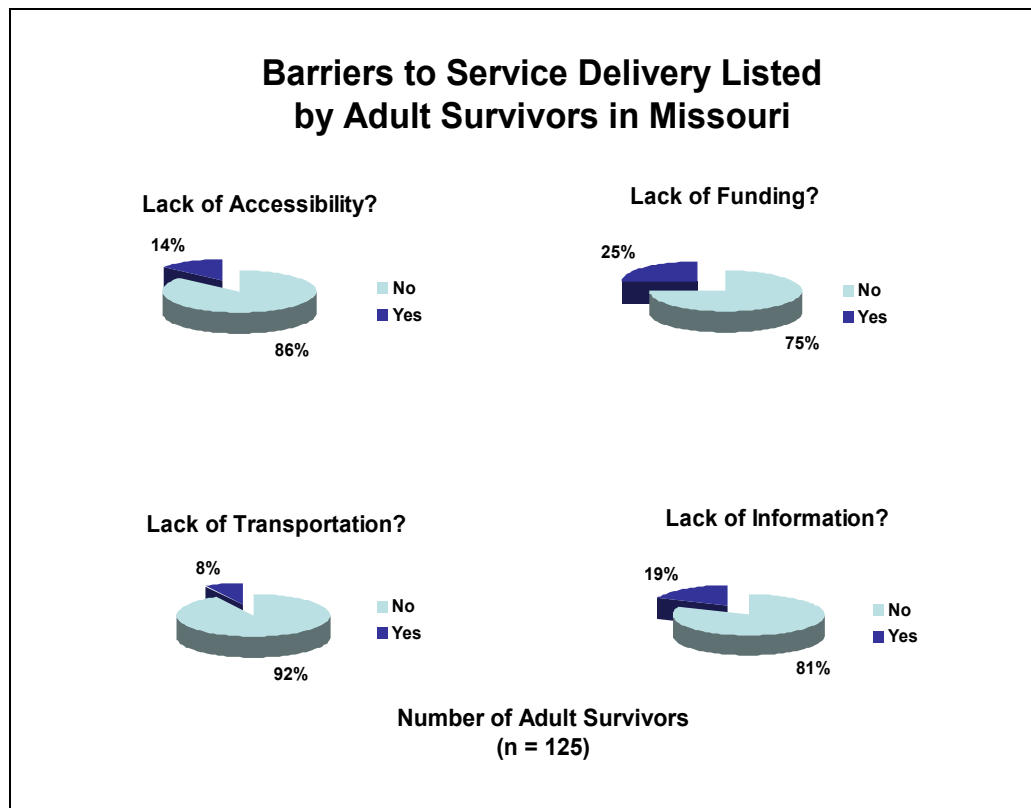


A majority of family members noted that they have trouble finding services, and that they are not currently receiving respite care. The following table reveals the percentage of interviewed family members, who reported concerns with these gaps in service delivery.

Service Delivery Gaps Listed by Family Members & Guardians in Missouri



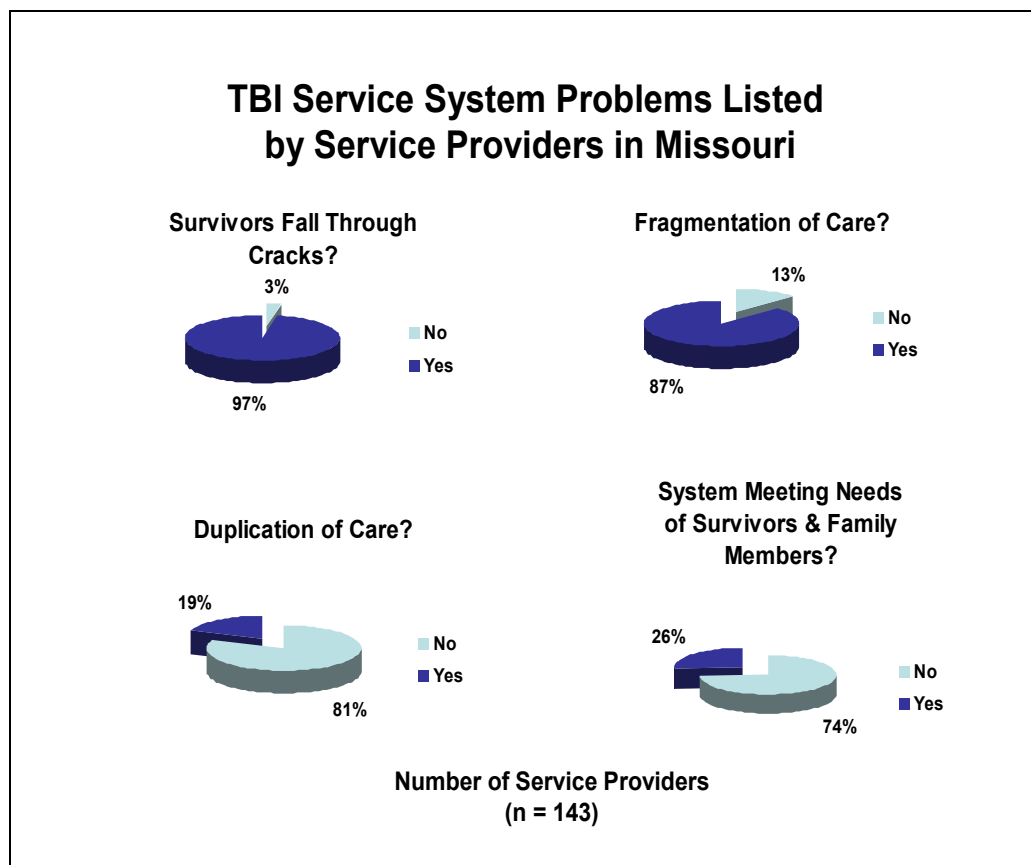
In contrast to reports from family members, the majority of adult TBI survivors did not mention a lack of accessibility, funding, transportation or information as barriers to service delivery. This finding conflicts with the focus group data for family members and adult survivors, and may result from the open-ended format of some phone survey questions rather than reflecting an actual absence of difficulty, since nearly all survivors interviewed in person expressed considerable difficulty with service barriers. One may refer to the following table to see the percentages of interviewed survivors, who reported concerns with barriers to service delivery in Missouri.



TBI service providers listed several areas that represent the “greatest unmet needs for TBI survivors and family members/guardians.” Reports from TBI service providers largely corresponded with data from family members. Paralleling the main barriers listed from

focus group data and anecdotal data from interviews, service providers note the following as the greatest unmet needs:

- life-long follow-up
- home health services
- one-on-one assistance
- housing and respite care
- funding and insurance
- 97% of providers said that TBI survivors “fall through the cracks”
- 87% of providers describe the current state of TBI care as “fragmented”
- Nearly 3/4 of providers said the current system does not meet the need of TBI survivors and families.
- education and information
- mental health counseling
- accessibility to services
- transportation options
- community support



B. Barriers to Services and Programs

Based upon the telephone interviews and focus groups, the project team found several key barriers to service delivery for TBI survivors, family members/guardians, and services providers in Missouri. The key barriers are the following:

- **Limited public knowledge of TBI,**
- **Lack of coordinated state TBI policies,**
- **Funding issues,**
- **Lack of post-acute TBI services,**
- **Lack of adequate family supports, transportation, and housing,**
- **Substance abuse,**
- **Traditionally underserved populations.**

In the remainder of this section, one will find detailed explanations of the barriers to services and programs shared by the interview and focus group participants. A list of data sources is provided in Appendix A. Recommendations to deal with these barriers and suggestions to improve TBI service delivery in Missouri are provided in the following section (Section VII, Discussion).

1. Limited Public Knowledge of TBI

Nearly all interviewees stated that a primary problem for persons with TBI in Missouri is the lack of knowledge regarding TBI by the public, health professionals in non-rehabilitation settings, state agency employees, and legislators. Specifically, concerns were reported that others do not understand TBI, do not know how to treat it, and are not aware of available resources for persons with TBI. Others often believe that TBI-related impairments (e.g., forgetfulness, irritability, personality changes) reflect negative personal characteristics or traditional mental health problems rather than TBI. As a result there is ineffective and inefficient provision of services, as well as a lack of comprehensive, coordinated TBI policies and services to promote adequate recovery, independence, and well-being. If services are to be improved for persons with TBI, initial and significant

efforts will need to focus on educating others regarding TBI and services needed to improve TBI outcomes.

Federal and State Legislators. Many TBI providers and administrators expressed concern regarding a serious lack of familiarity with TBI by state legislators. Since legislators are responsible for passing new laws, shaping public policy, and directing limited state resources, it is absolutely critical to make coordinated, grass-roots efforts to educate our state leaders about TBI and those services that are most effective in promoting well being in a cost-effective manner. Most legislators are laypersons with no training or expertise in TBI so it is not surprising that Missouri does not have coordinated public health policies to address the needs of persons with TBI in the state. It was nearly unanimously agreed that persons with TBI, service providers, and TBI advocacy organizations must do a much better job of educating legislators regarding TBI every year (and particularly new legislators), and help them draft legislation to promote coordinated TBI public health policies. Although several interviewees acknowledged efforts to influence legislation have improved in the recent past, many expressed a desire for better coordination among the Missouri BIA, the Head Injury Advisory Council, and other interested parties in the state. This is especially important given the recent implementation of term limits in the Missouri Assembly, which results in the need to educate and form partnerships with a large number of incoming legislators.

Health Service Providers. Almost all interviewees expressed general satisfaction with inpatient rehabilitation staff, given most professionals who work in these settings have had specific training and expertise in TBI. However, individuals with TBI and their family members reported that most of the health care providers from whom they received services outside of rehabilitation settings were not knowledgeable regarding TBI, and therefore survivors and families did not believe that they were receiving the most appropriate or best health care services. In general, interviewees reported that many of the physicians who treated them following their injuries, and particularly family medicine physicians, did not fully understand their problems. Participants also expressed concern that outside of inpatient rehabilitation settings, many rehabilitation therapists were not adequately trained in TBI issues, including occupational therapists, physical therapists, and speech pathologists. Similar concerns were reported that mental health professionals (e.g.,

psychologists, counselors, social workers, psychiatrists) in most outpatient settings do not understand the uniqueness of TBI-associated neuropsychological impairments, and as a result persons are frequently treated for traditional mental health problems (e.g., depression, anxiety) rather than TBI related impairments (e.g., loss of identity and self-esteem, changes in interpersonal relationships, behavioral issues, etc.).

State Services. A major concern was expressed that many service providers, and particularly those who work for state agencies that provide services to persons with TBI, are not knowledgeable regarding TBI, the common difficulties persons with TBI experience, or resources that are available to them. For example, interviewees reported concerns regarding state employees who work with persons with TBI to promote employment or who provide financial assistance. Staff from Disability Determinations make decisions regarding whether persons with TBI can work or not and if they should receive financial assistance, but they are not required to receive training in TBI. Similarly, Worker's Compensation staff make decisions regarding delivery of health and vocational services, as well as financial assistance, although persons with TBI and their families reported concern that these staff often do not understand the nature of TBI. Although the Missouri Division of Vocational Rehabilitation district offices have a designated TBI counselor, DVR staff no longer receive regular training in TBI (they did in the past). There is a need to ensure that state staff are able to adequately assist persons with TBI in returning to work successfully, or receiving adequate financial support for their disabilities, which will require consistent training in TBI for staff in these agencies.

Concerns were also raised regarding the limited knowledge of TBI by staff from state agencies which provide counseling, case management, and substance abuse services, including the Department of Mental Health (DMH) and Regional Centers. For example, DMH staff provide both substance abuse and traditional mental health treatment to Missourians of limited financial means, including persons with TBI. However, training in TBI issues is not regularly offered to or required for DMH staff. As a result, counseling is often provided that is inappropriate or ineffective, or services are terminated if persons with TBI exhibit problematic behavior related to their TBI (which may be the primary reason they seek counseling!).

Although Regional Centers primarily provide services to persons with developmental disabilities, they also often provide much-needed case management services to persons with TBI. However, Regional Center staff do not receive formal training in TBI. Persons with TBI and their families reported concerns that Regional Center staff often treat them as if they have developmental disabilities (i.e., those clients primarily served by Regional Centers), and as a result they often receive inadequate services (e.g., overemphasis on supported employment services).

Legal System Personnel. Many persons with TBI have post-TBI legal problems, although judicial and police system personnel (e.g., judges, police, attorneys, parole officers, etc.) receive little or no training in TBI. Concerns were reported that police often confuse TBI-related impairments (e.g., incoordination, confusion) with drunken behavior and that TBI-related problems are often confused with motivational or negative personality factors. Similarly, persons with TBI often have contact with the Division of Family Services related to child care issues, an extremely important issue for any person. Unfortunately, DFS caseworkers are not regularly trained in TBI, do not understand the behavioural problems that often accompany TBI, and may not arrange for the most appropriate behavioural management services (if they can even be purchased). It should be noted that legislation was passed in the Fall of 2004 that mandates mental health training for certain federally-funded law enforcement personnel. Ideally, TBI training could “piggyback” on these training contracts to ensure that law enforcement officers receive training in TBI through sustainable programs involving modest additional cost.

Educators. Specific concerns were raised by several interviewees regarding the lack of knowledge and appropriate services for children and adolescents with TBI, including limited knowledge of TBI by teachers, school administrators, school counsellors, and special education staff. It was noted that many schools provide excellent services to children and adolescents with TBI, although others were either lacking in basic knowledge about TBI and appropriate interventions or unwilling to provide such services. It was agreed that school personnel need a standard resource from which to learn about TBI services, accommodations, and resources for students with TBI. Training in TBI issues for educators has for the past several years been conducted on request by the Center for Innovations in Special Education. Unfortunately, funding for this TBI school personnel

training program was recently cut, despite the substantial investment the Center had made in developing and delivering effective educator training modules.

2. Lack of Coordinated State TBI Policies

Many health service administrators and providers reported concerns about the lack of coordinated legislative efforts and state agency services to address the needs of persons with TBI. It was generally agreed that Missouri has numerous helpful state programs and advocacy agencies for persons with TBI (e.g., MO Head Injury Advisory Council, MO Brain Injury Association, TBI Service Coordinators, Division of Vocational Rehabilitation, Independent Living Centers, etc.), but that too often these groups work in isolation. Participants also expressed concern that payment for services is fragmented, which leads to inefficient delivery of necessary services. In a nutshell, different state programs are restricted in what they can purchase or provide for their clients, and as a result the comprehensive needs of persons with TBI are inadequately addressed.

TBI Legislative Agenda. A specific, coordinated legislative agenda for persons with TBI has yet to be developed, although all constituencies appear to realize the importance of this and are beginning to address this issue. The lack of a **specific TBI legislative agenda** is likely partly related to the fact that most state legislators are laypersons with little if any understanding about TBI, and they will not advocate for different causes without knowledge of the issues and/or pressure from their constituents. If legislative gains are to be made, TBI advocates need to organize to develop a legislative agenda, develop a grass roots advocacy network, and make personal contact with their legislators.

State Agency Coordination. Concerns were expressed that the state programs that serve individuals with TBI are lacking in coordinated services to best meet their clients' needs. In general, individual state TBI programs were reported to offer and pay for adequate services to address one specific area of need (e.g., vocational rehabilitation, financial support, health services), although it was believed that they could more effectively coordinate efforts. For example, the state of Missouri does not have a **uniform definition of TBI** to be used by all state departments to determine individuals' diagnostic eligibility to receive services. The necessity of completing different and redundant forms

for different state agencies was reported to be very frustrating for persons with TBI, and interviewees expressed a willingness to work with state agencies to develop **one eligibility form for all state services**. The Department of Health and Senior Service has begun to remedy this problem by focusing on a common consent form across agencies and beginning to conceptualize a common database, but at present state information systems cannot and generally do not communicate with each other effectively.

In addition, concerns were stated regarding the need for a **standard state network referral system** by which individuals with TBI can learn about and access needed state services. Many families have no knowledge regarding TBI and do not know what services exist or where to access them. It is necessary to work with all hospitals and state programs that provide services to Missourians with TBI to establish a standard TBI referral system, which may be most appropriately directed by the Bureau of Special Health Care Needs.

State programs that provide services to persons with TBI often require and purchase different and redundant diagnostic evaluations. For example, DVR and DD often share the same clients and mutually determine if individuals can work or if they are disabled and in need of financial support. Persons often undergo multiple, similar evaluations when one would suffice. It will save state agencies time and money if they **coordinated services and shared information** (e.g., standardize psychological evaluations). In addition, such better coordination will be more consumer-friendly for their clients.

State University Collaboration. Several academic health professionals and state administrators expressed a need for more participation by the state university system in addressing the needs of individuals with TBI. This was believed to be necessary given the University of Missouri's mandated mission to meet the needs of Missourians, which is the reason they receive state financial support. Missouri is fortunate to have strong TBI interest and expertise in its universities. Such collaboration is also important given the resources available in the university systems. Collaboration with the state universities, as well as from any interested private academic institutions, will be particularly important in order to conduct the demonstration and research projects that will be necessary to promote the TBI legislative agenda.

3. Funding Issues

As expected, there were universal concerns expressed regarding the lack of adequate funding for almost all services for persons with TBI, and particularly for long-term, non-medical services. However, it is necessary to acknowledge that in order to increase funding for TBI services there must first be efforts to increase understanding that TBI is a life-long disability. This can be best accomplished by establishing grassroots advocacy networks to educate legislators regarding TBI issues, and by completing demonstration and pilot projects that demonstrate the efficacy and cost-effectiveness of requested services.

Many interviewees expressed concerns that insurance sources (private and state) primarily provide financial support for the acute physical injuries associated with TBI, but provide only limited and short-term funding to address cognitive, emotional, and behavioral issues that are frequently the primary barriers to successful independent living and employment. As a result of this focus on short-term funding, individuals with TBI have difficulties paying for adequate housing and basic living expenses, which in turn leads to significant financial burdens for their families.

Private Insurance. Most participants, and particularly physicians, stated that they did not believe insurance companies provided enough coverage for adequate inpatient treatment for persons with TBI. Such short stays may be appropriate to treat the acute physical problems associated with TBI, although they are not adequate to evaluate and treat the chronic neuropsychological problems associated with TBI. Participants expressed concern that funding of limited and short-term TBI services may be “penny-wise but pound-foolish.” TBI service coordinators and health care providers expressed a belief that such funding limitations are the result of the conceptualization of TBI as an acute disorder, in contrast to a lifelong condition. Several physicians expressed a belief that too few psychiatrists serve on insurance company review panels, and that some of these financial reimbursement difficulties will improve if this issue is addressed.

Concerns were also reported regarding the limited number of outpatient visits for rehabilitation services that are typically authorized by insurance companies. Specifically, significant functional and neuropsychological difficulties experienced by persons with TBI are often chronic, but insurance companies only authorize a very limited number of outpatient treatment sessions (e.g., occupational therapy, cognitive/speech therapy, or

psychological counseling) which are not adequate for many persons with long-term significant impairments.

Medicaid Reimbursement. As expected, general concerns were stated that Medicaid does not provide adequate funding to promote recovery from TBI. However, most interviewees understood that such funding concerns are reported by most individuals who receive Medicaid, regardless of their medical condition. A primary concern reported by persons with TBI and their service providers was that Medicaid currently reimburses only for outpatient physical therapy, but not for outpatient occupational or speech therapy. The rationale for this restricted reimbursement is unclear, and it can be argued that these other therapies are just as, if not more, important for persons with TBI who have ongoing cognitive, language, and functional difficulties.

Medicaid will also pay for mental health services administered via telehealth by psychiatrists, which is an excellent method to address accessibility issues and particularly in rural areas. However, Medicaid will not reimburse other mental health professionals, thus greatly limiting accessibility of necessary behavioural health services.

Persons with TBI also expressed frustration that many health care providers were unwilling to provide services to individuals with Medicaid due to poor reimbursement rates, and that Medicaid will only reimburse transportation contractors for driving individuals with TBI to medical but not rehabilitative appointments.

Flexibility in Payment. Several state agency personnel expressed frustration over their inability to purchase necessary health and rehabilitation services for their clients with TBI. For example, TBI service coordinators noted that inflexible guidelines sometimes prevented them from authorizing services they and their clients believed were needed. In a similar vein, DVR counselors are limited to reimbursing behavioral health services for only those cases with the severe psychological issues, although most counselors expressed concern that behavioral and cognitive problems are frequently the primary reasons individuals cannot work. More flexibility would enable individuals and families with TBI to receive tailored services that are aligned with their needs and goals.

TBI Service Coordinators. In general individuals were pleased with the services offered by TBI service coordinators, and health professionals applauded the creation of these positions to serve as case managers for persons with TBI. However, it was

universally agreed that there are not enough TBI service coordinators. There are only nine service coordinators to cover 114 counties in Missouri and they have no secretarial support. Some participants noted that more TBI service coordinators would mitigate the long delays some families experience in communicating with their service coordinator. TBI service coordinators also reported concerns regarding what they considered to be too many restrictions on the services they can purchase for their clients, and expressed a desire for more flexibility in how program monies can be spent. They further reported that they believed that the criteria to receive services are too stringent and should be relaxed.

Programs for TBI-Related Behavioral Problems. TBI service coordinators and family members reported concerns about the lack of inpatient programs specifically for individuals with significant TBI-related behavioral problems. Few such programs exist and they can accommodate only a relatively small number of individuals at any one time. It was reported that many persons with such problems are sent to inpatient behavioral programs in neighboring states, which is expensive for Missouri funding agencies. In addition, sending Missourians to different states away from their families is not an adequate solution because of the hardships associated with visiting and the lack of family-centered follow up. However, several hospital administrators and physicians stated that the high staff-patient staffing levels required for such programs, as well as low levels of reimbursement, make creation of more such units in Missouri financially unfeasible.

4. Lack of Post-Acute TBI Services

Almost all participants expressed significant concerns regarding the lack of long-term post-acute services to deal with the chronic difficulties experienced by persons with TBI. In addition to a general lack of funding, it was reported that problems receiving adequate post-acute services were due to lack of coordinated policies to fund and provide long-term post-acute care, limited availability of outpatient treatment programs, and lack of or inappropriately trained rehabilitation professionals in most outpatient settings.

Outdated TBI Service Delivery Model. A basic issue related to the lack of post-acute services for persons with TBI appears to be related to current health care policies that conceptualize TBI as a disease (e.g., heart attack) which is most effectively treated and cured with intensive and time-limited medical services. However, this model lacks

recognition of the fact that TBI is a chronic health condition that requires substantial long-term services to promote adequate recovery, and that persons with TBI are not “cured” after a limited number of outpatient therapy visits. Many interviewees argued that most rehabilitation and behavioral health services (vs. medical ones) are most needed months and even years after their acute physical problems have been effectively treated, and when they attempt to return to home, work, school, and community activities. Therefore, there is a need for state agencies and insurance companies to reconceptualize TBI as a health condition that necessitates long-term care and case management services, possibly similar to the Regional Center case management model for individuals with developmental disabilities or Dept. of Health and Senior Services case management for elderly individuals.

Transitional Services. Participants argued for **the need to develop transitional programs** for persons with TBI after they have been discharged from inpatient settings but before they are ready for outpatient day treatment programs. This problem stems from the fact that individuals with TBI are being discharged sooner from inpatient programs and often return home or to other residential facilities with ongoing and considerable physical, medical, and neuropsychological issues which preclude them from attending outpatient programs. This is especially true given the relatively short length of hospitalization for most persons with TBI. Many of these individuals are not yet appropriate to receive outpatient services and can be argued to be in programmatic “limbo” with no place to receive services. Rather than receive no services, which can negatively impact their recovery, there is a need for transitional rehabilitation services to be provided between participation in inpatient and outpatient programs.

Lack of Day Treatment Programs. There was near unanimous agreement that there is a significant need for **more day treatment and assisted living programs** after individuals have recovered from their acute physical injuries and when they are attempting to re-integrate into their communities. Many TBI administrators and service providers stated that this lack of outpatient day treatment programs is primarily related to funding issues, and that the state and insurance companies are going to need to provide adequate financial funding if more outpatient programs are to be developed.

TBI Expertise in Non-rehabilitation Settings. Interviewees generally reported that outpatient rehabilitation services were adequate if delivered by staff within rehabilitation settings, but **problems existed when individuals sought services away from rehabilitation facilities**, as is often the case for individuals who live long distances from the hospitals where they received their inpatient rehabilitation. Most individuals must seek outpatient rehabilitation services at community hospitals, community health clinics, private practices, or even nursing homes, although previous research in Missouri has indicated that there are relatively few rehabilitation professionals to provide services, with many rehabilitation services provided primarily by assistants rather than licensed professionals. This is particularly the case in rural areas.

Long Term Behavioral Health Services. Participants reported concerns about the **need for long term behavioral health services for persons with TBI and their families**. Physical impairments improve sooner than neuropsychological problems, and can be more easily treated with assistive devices than neuropsychological impairments. Conversely, emotional, behavioral, and cognitive difficulties persist months and years after TBI, and often are exacerbated in the long term as individuals have problems coping with their injuries, returning to work, maintaining relationships, and socializing with an often diminishing group of friends.

Problems in the adequate delivery of behavioral health services are related to both workforce and financial factors. Interviewees and previous research both indicate that there are very few mental health professionals with expertise in TBI to provide mental health services in Missouri, and particularly rural Missouri (Johnstone, Nossaman, & Schopp, 2002). Most **mental health providers have little or no training in TBI issues** because psychologists, counselors, social workers, and psychiatrists are primarily trained in traditional mental health disorders (e.g., depression, anxiety). Consequently, they may provide inappropriate treatment that does not effectively address those psychological issues that are most relevant to persons with TBI (e.g., cognitive remediation, adjustment to changes in personality, self-concept, self-esteem, social relationships, etc.).

From a financial perspective, insurance companies typically authorize only a limited number of behavioral health services per year, thus creating a “band-aid” approach to dealing with the psychological problems individuals and families with TBI encounter.

Similarly, Medicaid, which is the primary health system for persons with TBI, will only pay for mental health services offered in community health centers. However, community mental health centers generally employ only mental health “generalists” who are trained to provide services for traditional mental health disorders such as depression and anxiety disorders.

5. Lack of Adequate Family Supports, Transportation, and Housing

Family Support. Families of individuals with TBI reported concerns regarding a **lack of basic resources and supports for families**. Family members often have little or no knowledge regarding TBI, are unsure how to deal with the cognitive, emotional, and behavioral impairments associated with their family member’s TBI, and are unaware of supports and resources they can obtain to assist them as caregivers. Research has indicated that persons with TBI in general have more limited financial resources and education than the general population even before their TBI, with financial problems only increasing after their TBI. In turn, these financial difficulties usually present additional and significant financial pressures for family members. For example, family members reported having to spend more of their own resources on persons with TBI and needing more time to care for their family member, which in turn lead to a secondary loss of income for the family. Furthermore, family burnout is reported to be high given the limited respite and support services that are available for families.

Transportation. Nearly universal problems were reported regarding the lack of transportation for persons with TBI, particularly in rural areas but also in urban areas. It was also recognized that this is a very difficult problem that has no easy solutions. Many individuals with TBI cannot drive due to medical restrictions (e.g., seizures), cognitive impairments (e.g., inattention, judgement or perceptual difficulties), or financial reasons (e.g., lack of an automobile, inability to purchase insurance, limited resources and need to prioritize other basic living needs). Furthermore, there are very **limited public transportation options**, as public bus systems are frequently inadequate in availability (i.e., location of routes and frequency of buses). Public transportation options in rural areas have been shown to be virtually nonexistent in Missouri (Johnstone, Nossaman, and Schopp, 2001), and other transportation options (e.g., OATS bus) are limited by restrictions

on the types of disabilities served. The lack of adequate transportation has far-reaching effects on persons with TBI, as they often cannot get to work, attend medical/rehabilitative appointments, complete basic tasks such as shopping, or socialize. Such transportation difficulties often lead to secondary disabilities, including worse health and increased psychological problems, which in turn can lead to increased long-term medical and substance abuse costs for the state.

Medicaid does allow for reimbursement for private contractors to drive Medicaid recipients to medical appointments, which is very useful for many individuals. However, such services can only be purchased for medical appointments, but not for rehabilitation or mental health services. In addition, several TBI service coordinators reported that the contracted drivers have had difficulties in securing reimbursement in a timely manner.

Housing. Due to the financial difficulties previously described, there are limited housing options for persons with TBI. Individuals with TBI often cannot maintain their mortgage/rent payments due to an inability to work and often need to find new and **more affordable and appropriate housing**. Often this necessitates them moving into family members' homes, thus creating additional financial problems for their families and lack of independence for survivors. Concerns were also reported regarding a lack of appropriate housing options for individuals after they are discharged from acute hospitalization, with nursing homes being the only option for many individuals.

6. Substance Abuse

Participants reported widespread concern about significant substance abuse problems among the population of TBI survivors, as well as the lack of appropriate substance abuse treatment services. For example, there is only one CSTAR program in Missouri that is specifically tailored for the needs of persons with TBI. The only TBI-designated CSTAR program is in rural southwest Missouri and is not well known to others throughout the state. Most individuals with TBI do not want to travel such a long distance and be away from their families. Many participants expressed the need for more substance abuse programs for people with TBI, and particularly ones that are accessible and more evenly distributed throughout the state.

It was reported that the Department of Mental Health provides substance abuse services to all persons with substance abuse problems in the state, including persons with TBI. However, many interviewees reported general concerns that Department of Mental Health counselors are not adequately trained in TBI issues. Similarly, concerns were reported about the relative inability or unwillingness of substance abuse counselors to address TBI-related behavioral issues concurrently with substance abuse problems. However, many persons with TBI present significant behavioral issues related to both their TBI and substance abuse, and as a result are asked to leave treatment. This lack of integrated dual diagnosis programming is self-defeating and needs to be addressed.

7. Traditionally Underserved Populations

In addition to concerns expressed above, other concerns emerged that may be best summarized as the needs of traditionally underserved populations. For example, numerous participants raised concerns about the **lack of knowledge regarding children and adolescents with TBI**, the lack of pediatric rehabilitation professionals, and the lack of expertise in TBI in school districts. Unfortunately, this unmet need is consistent with limitations in availability of pediatric TBI services and professionals across the nation.

Participants expressed further concern about the **overall poor resources availability for members of minority groups with TBI**. Some participants cited a sense of alienation or unfamiliarity with the existing TBI service structure among racial and ethnic minority group members. This lack of connection to service structures may increase the vulnerability of minority group members to unfavorable TBI outcomes, and may increase the stress on minority families with TBI.

Frequent references were made regarding the **unique problems faced by persons with TBI in rural areas**, including limited accessibility to services, few rehabilitation professionals with TBI expertise, lack of transportation services, and limited employment opportunities.

Members expressed further concern about the **lack of resources for persons with mild TBI**. Since mild TBI represents the overwhelming majority of persons with TBI, it is necessary to improve the flow of information for persons with mild TBI who are treated and released from emergency rooms.

C. Missouri Initiatives

The following initiatives are underway in Missouri in hopes of furthering the improvement of service delivery and access to services for individuals with TBI and their families:

- Common Diagnostic Definition – efforts to create a common diagnostic scheme across state agencies. Currently, this initiative is not fully implemented.
- Informatics – efforts to create a common data set that is inter-agency defined for TBI services. This initiative has been partially implemented. DHSS has been the lead agency on this initiative.
- Common Form – efforts to create a common form to facilitate interagency cooperation. This initiative has been fully implemented. DHSS has been the lead agency on this initiative.

VII. Discussion

A. Recommendations

Based upon the data sources including interviews and focus groups with TBI survivors, family members/guardians, and service providers in Missouri, the team created a list of recommendations in relation to the key barriers. In this section, one will find a detailed explanation of the recommendations. The following is a summary table of the barriers and the main recommendations:

Barriers	Recommendations
10. Lack of accurate TBI Incidence & Prevalence Estimates	<ul style="list-style-type: none">• Improve Resources to Maintain Existing TBI Databases• Expand TBI Reporting Mandate to Acute Rehabilitation Hospitals• Supplement Hospital-Based Data with Community Survey Data
11. Limited Public Knowledge of TBI	<ul style="list-style-type: none">• Create uniform educational materials on TBI• Create one uniform Missouri TBI website• Initiate marketing campaign to promote awareness of the single site• Require annual training in TBI for state employees and ongoing education• Offer TBI presentations at the state and regional conferences of other professions• Designate staff member in district offices to be the TBI-designated service provider• Utilize existing telehealth networks to increase accessibility

	<ul style="list-style-type: none"> • Identify celebrities who can promote services for persons with TBI • Advocate to restore funding to the Center for Innovations in Special Education
12. Lack of Coordinated State TBI Policies	<ul style="list-style-type: none"> • Develop a TBI Advocacy Network with participants from all TBI constituencies • Develop a legislative agenda for those issues that need to be addressed • Develop a TBI grassroots network, with individuals from each county in the state • Develop a TBI grassroots legislative listserv • Identify legislators who are willing to sponsor TBI-related legislation • TBI advocacy agencies consider hiring a part-time lobbyist • TBI Advocacy Network request meetings with relevant state agencies • TBI Advocacy Network request meetings with state agencies • Arrange MU Post-Acute Network
13. Funding Issues	<ul style="list-style-type: none"> • Insurance policies conceptualize TBI as a condition that requires long-term services • Demonstrate efficacy of services through pilot and demonstration projects • Increase the number of TBI service coordinators • Conduct demonstrations projects • Members of the TBI Advocacy Network meet with insurance and managed care • Conduct analysis to determine Missourians seeking TBI-related treatment and costs • Increase the number of such TBI-related programs in the state and visibility
14. Lack of Post-Acute TBI Services	<ul style="list-style-type: none"> • Promote conceptualization of TBI as a chronic health condition • Promote a case management system for persons with TBI • Each Regional Center employ a case manager with expertise in TBI • Convince state and private insurance providers of benefits of programs • Provide TBI continuing education programs to professional associations • Expand debt forgiveness programs for rehabilitation professionals • Educate rehabilitation professionals of existing federal debt forgiveness programs
15. Lack of Adequate Family Supports, Transportation, and Housing	<p><i>Housing Issues</i></p> <ul style="list-style-type: none"> • Partner with agencies that provide housing for persons with developmental disabilities • Greater partnership between TBI service coordinators and ILCs • Examine Medicaid waiver program eligibility criteria

	<ul style="list-style-type: none"> • Develop group home options for persons with TBI in the community <p><i>Family Support Issues</i></p> <ul style="list-style-type: none"> • Evaluate the existing Early Support Partnership Program • Examine the structure and implementation of intervention programs in other states • Develop resource packets to distribute at all hospitals • Develop a website that lists all available family supports by county • Work with the MO Brain Injury Association to form support groups in rural areas • Work with the Missouri Telehealth Network to coordinate state-wide TBI support groups. <p><i>Transportation Issues</i></p> <ul style="list-style-type: none"> • Develop and evaluate efficacy and cost-effectiveness of transportation models • Develop novel hybrid public-private partnerships • Develop web-based resources that list all transportation options by community • Re-evaluate existing Medicaid transportation reimbursement policies • Work with Medicaid to improve the timeliness of payments for Medicaid • Work with DVR to evaluate home-based work options for individuals with TBI • Work with state TBI researchers to propose transportation demonstration projects
16. Substance Abuse	<ul style="list-style-type: none"> • Advocate for more CSTAR programs specifically for persons with TBI • Improve marketing for the existing substance abuse program at MRC • Require annual training regarding TBI for DMH substance abuse counselors • Improve behavior management programs in substance abuse programs • Improve the integration of substance abuse services into existing TBI treatment
17. Traditionally Underserved Populations	<ul style="list-style-type: none"> • Formation of a pediatric special interest group of the MOHIAC • Update MO-BIA database for self-identification as a racial or ethnic minority • MOHIAC and BIAMO partner with MU's Extension office to reach rural areas • Develop and distribute a very brief handout listing resources for mild TBI
18. Statewide TBI Action Plan	<ul style="list-style-type: none"> • Key stakeholder groups form partnership to put in place an action plan with key goals, timelines, and specific objectives and designees responsible for activities

1. Recommendations to Improve TBI Incidence & Prevalence Estimates

Because Missouri's current surveillance system relies heavily on hospital-based studies, the current Missouri system is unable to capture and record cases of mild TBI. Further limiting the scope of reported TBIs is the fact that some Missouri hospitals, though required to report TBI, do not report their cases to the Registry. Many small community hospitals are not required to report TBI at all. Therefore, the Registry is unable even to capture hospitalized cases of TBI, much less persons who received treatment in community settings or received no treatment.

In 2003, the CDC published an extensive report to Congress on the impact of mild TBI, including a review of the comprehensiveness of current TBI data collection systems (CDC, 2003). The report summarizes the existing surveillance data efforts, listing the strengths and weaknesses of each type of surveillance system.

Missouri's surveillance system has strengths in that it relies on existing reporting systems and has enabling legislation allowing for mandatory reporting. Another strength is its integration into the Missouri Information for Community Assessment (MICA) data acquisition and display project, which makes TBI data accessible to the public in a highly usable and customizable format. Indeed, the MICA project leads the nation in novelty and accessibility of public health data, including data on TBI.

a. Improve Resources to Maintain Existing TBI Databases

Despite these strengths, the quality of currently available Missouri TBI data is problematic for several reasons. First, the Missouri Dept. of Health and Senior Services lacks adequate staffing to meet the maintenance and acquisition needs of existing TBI databases. If the current Trauma and TBI Registries are to be maintained and the data to be kept current, it will almost certainly require an increase in the staffing available to these programs. With current staffing levels, the timeliness of TBI is compromised to such an extent that the Registry is at least three years behind in posting TBI data.

b. Expand TBI Reporting Mandate to Acute Rehabilitation Hospitals

A second area of concern is that there is not currently in place a mechanism to integrate hospital-based TBI data with data from other sources, such as rehabilitation hospitals and nursing home settings. Including a broader population-based estimate would improve TBI documentation and, if done properly, could prevent duplicate entries on the same person. It would be worthwhile to consider extending the reporting mandate at least to major acute rehabilitation hospitals (with mechanisms to prevent duplicate entries from trauma centers), since extending reporting mandates to nursing homes would prove unwieldy. By including reports from acute rehabilitation hospitals, and by extending the mandate to include any report of TBI (not just among primary diagnoses), the current tracking system can improve the likelihood that persons whose TBI only becomes evident during acute rehabilitation after trauma center discharge will be counted.

c. Supplement Hospital-Based Data with Community Survey Data

A final area of concern centers on the absence of prevalence data from random population surveys. Data from these surveys can serve to balance the current bias toward reporting only moderate to severe TBI for which a patient is hospitalized. At present, Missouri has in place population survey mechanisms such as the Behavioral Risk Factor Surveillance System. An advantage of the Behavioral Risk Factor Surveillance System is that it can be modified to include TBI questions and preliminary data analysis for approximately \$5,000 per question (the rate drops to \$4,500 per question if the request is made by a member of the Missouri Department of Health and Senior Services), and its community sample includes persons who were not treated in a hospital or emergency department setting, i.e. persons with mild TBI. The Behavioral Risk Factor Surveillance System can be modified to collect data from adults with TBI, as well as parents and guardians of children with TBI. The Behavioral Risk Factor Surveillance System provides representative data for Missouri. To the extent that Missouri models its TBI-related questions on standard questions being used by other states, and to the extent that other states also use these questions, it, can produce nationally representative data as well. We recommend that the Behavioral Risk Factor Surveillance System be considered as a

relatively economical supplement to data from existing Missouri Registries. Doing so will allow for better prevalence estimates for TBI in the general Missouri population.

This study worked to identify error sources in the investigation of TBI incidence and prevalence, and identified the simplest, least resource-intensive ways to improve Missouri's access to current, comprehensive, and high-quality data on TBI. In implementing these recommendations in accordance with published CDC standards for TBI surveillance, Missouri can capitalize on its superb information dissemination infrastructure to offer timely, accurate TBI data. Such data will enable Missouri to track effects of prevention programs, as well as conduct effective program planning based on the level of need for TBI-related services.

2. Recommendations to Remedy Limited Public Knowledge of TBI

Throughout all the interviews it became clear that in order to adequately address the many different deficiencies in the delivery of services to persons with TBI, it will be necessary to first better educate Missourians regarding TBI. Without proper knowledge of TBI, adequate solutions will not be identified and developed.

- **Create uniform educational materials on TBI that are easily understandable for laypersons, state agency staff, and non-rehabilitation health professionals.** Written materials should be available for dissemination and include information on basic neuroanatomy, common TBI-related impairments (e.g., headaches, cognitive/language difficulties, behavioural problems), standard interventions, and available financial, health, vocational, and resources and supports (including how and where to apply for them). Educational materials should be available in every hospital and rehabilitation facility in the state, and in the district offices of all state agencies that serve persons with TBI.
- The MO-Brain Injury Association, MO Head Injury Advisory Council, and state university should collaborate to create **one uniform Missouri TBI website which provides standard information about TBI, common impairments and associated treatments, and available resources and supports for every county in Missouri.** Such a site should, to the greatest extent possible, capitalize on

existing training materials. All state agencies that provide services to persons with TBI should provide web-based links to such a website. The Head Injury Advisory Council would need to secure funding to maintain current information on this website.

- The MO Head Injury Advisory Council has recently put in place an excellent billboard-based marketing campaign to reach the general public. After uniform educational materials and one standard TBI website are created, a **marketing campaign should be initiated to promote awareness of the single site.** Coordinated efforts will be necessary to ensure all hospitals, health professionals, state agencies, and advocacy organizations are aware of and use these materials and websites. Efforts should be made to arrange for public service announcements on television and radio programs, and TBI advocates should coordinate regional efforts to increase awareness of TBI issues across the state via local newspapers and television and radio programs.
- State agencies that provide services to persons with TBI should be persuaded to **require annual training in TBI for their employees** (e.g., Dept. of Health & Senior Services, Dept. of Mental Health, Division of Vocational Rehabilitation, Disability Determinations, Division of Family Services, police, parole officers, public attorneys, etc.). Training can be provided at annual conferences, through specific TBI-related training programs, or through self guided web-based training sites. Given the mission of the state universities to meet the needs of Missouri citizens, they should be strongly encouraged to develop and provide such training materials in collaboration with other TBI advocacy organizations. University employees should be encouraged to provide such training for free or at cost.
- To ensure that all future health and rehabilitation professionals are trained in TBI, **all medical, nursing, and health professional training programs in the state should offer academic coursework in TBI.** Efforts should be made to arrange for meetings with all medical, nursing and health professional training programs in the

state to persuade them of this necessity and to provide them with the suggested educational materials. Additional TBI-related training could be made available as part of these state associations' annual conferences.

- State TBI agencies, state universities, and the MO-BIA should collaborate to offer **TBI presentations at the state and regional conferences of other professions** that provide services to persons with TBI such as judges, attorneys, physicians, psychologists, nurses, rehabilitation therapists, social workers, licensed professional counselors, etc.. Continuing education offices at state universities provide an excellent platform for such training and outreach to currently licensed health professionals,.
- Primary state agencies that provide services to persons with TBI should **designate at least 1 staff member in district offices to be the TBI-designated service provider** (similar to the previous Division of Vocational Rehabilitation model).
- When offering educational programs, it is recommended that existing **telehealth networks be utilized** (and particularly in rural areas) to increase accessibility to such training programs, as well as to decrease attendees' costs and time commitments. Missouri has a telehealth network that has won national recognition and that exists to serve the service and training needs of Missourians.
- To help increase the public's awareness of TBI, it may be helpful to **identify celebrities who can promote services for persons with TBI**. For example, Ben Vereen has been an excellent spokesperson for persons with stroke. Continued efforts should be made in conjunction with the BIA of the United States of America to identify spokespersons who can increase interest in TBI in Missouri.
- **Advocate to restore funding to the Center for Innovations in Special Education educator training program** through the Department of Elementary and Secondary Education. This is the only program of its kind in Missouri to

provide training for educators to help them meet the needs of a child returning to school after TBI.

3. Recommendations to Remedy the Lack of Coordinated State TBI Policies

Suggestions were made to establish a formal working group of all the above TBI constituencies (hereby labelled the TBI Advocacy Network) to determine those issues that are most important to address for persons with TBI, the desired outcomes that need to be achieved, and the methods by which to achieve them. Several individuals expressed strongly the need to develop specific action plans to address reported concerns, as in the past concerns have been expressed to legislators (e.g., 1999 legislative hearings), although there has been only minimal follow-up to ensure that all concerns are being addressed. It should be noted that efforts have been made over the past decade in all these areas, but a coordinated, sustained effort is needed if substantial progress is to be made.

- To be most effective in promoting TBI legislation, it will first be necessary to **develop a TBI Advocacy Network** with participants from all TBI constituencies in Missouri, including persons with TBI and their families, TBI advocacy agencies (e.g., MO-BIA), volunteer TBI service organizations (e.g., Centers for Independent Living), state agencies (e.g., MO Head Injury Advisory Council, Bureau of Special Health Care Needs TBI service coordinators, Division of Vocational Rehabilitation, Disability Determinations, etc.), public and private universities, TBI researchers, health care professionals, and legislators.
- Using this report as a starting point, it will be necessary to **develop a legislative agenda** for those issues that need to be addressed in the legislature and across state programs that serve individuals with TBI.
- It will then be necessary to develop a **TBI grassroots network**, with individuals from each county in the state identified to serve as contacts for each state representative and senator.

- A **TBI grassroots legislative listserv** could be developed (in contrast to general TBI listservs) in order to provide timely information about pending legislation and contact information for all legislators. The network should include memos with main points to be conveyed to legislators, as well as copies of sample draft letters. Personal contacts with legislators should be promoted to convince legislators of the need for the requested legislation, as well as to help them draft and sponsor it. This effort could be done in conjunction with similar work by the Missouri Assistive Technology project.
- Legislators should be identified who are willing to sponsor TBI-related legislation and help direct state policies which affect persons with TBI. If possible, it may be most helpful to **identify legislators with personal experience with TBI** (e.g., family member, friend with TBI).
- TBI advocacy agencies (e.g., MO-BIA) could consider hiring a **part-time lobbyist** to assist them in promoting TBI issues in the state. This may be necessary given the number of organizations seeking the support of their legislators, and existing state budget constraints.
- The TBI Advocacy Network will need to request meetings with relevant state agencies to **address the lack of coordination among programs and lack of TBI training** for their staff. For example, a meeting with all state programs that provide services to persons with TBI should be requested to create one *eligibility* form for persons with TBI to use across all state programs (in addition to the current interagency *consent* form), and to develop a single state-wide definition of TBI and uniform diagnostic criteria to determine eligibility to receive services for TBI. The state has already consolidated many related state programs into one building in many communities in Missouri (i.e., one-stop centers), and in the same spirit they should now be encouraged to develop one core application form for all programs that serve persons with TBI, with additional supplemental modules as needed by each agency.

- The TBI Advocacy Network could request meetings with state agencies to **encourage streamlining of services and better coordination** among them. For example, a meeting with Division of Vocational Rehabilitation and Disability Determinations staff could be arranged to encourage them to better coordinate evaluations, based on the belief that such coordination will be easier for clients and more cost-effective for the state. Similarly, a meeting with TBI service coordinators and Regional Center staff could enhance case management services for persons with TBI.
- A meeting with the MU Health Care Post-Acute Network should be arranged to determine how MU Health Care can help to meet the needs of Missourians with TBI, including staff from MU Health Care, the Missouri Telehealth Network, and the Missouri Rehabilitation Center. The MU Health Care Post-Acute Network should work in concert with rehabilitation facilities in St. Louis, Kansas City, Springfield, and other areas of the state to **ensure the best possible service coverage for all state residents**.

4. Recommendations to Remedy Problems with Funding Issues

It must first be acknowledged that it will be difficult to change funding limitations for persons with TBI, given continued rising health care costs, tight state budgets, and the fact that many other health advocacy organizations are also seeking increased funding for their respective causes.

- Any real changes in funding for TBI will remain unlikely as long as current insurance policies continue to conceptualize TBI as an acute physical disorder that can be effectively treated in a time-limited fashion. Instead, they will need to be convinced **to conceptualize TBI as a condition that requires extended long-term services** to treat non-physical problems.
- In order to justify increased financial resources for TBI resources, it will be necessary to **demonstrate the efficacy of services through pilot and**

demonstration projects. It is recommended that a conference be arranged and include persons with TBI and their families, TBI researchers, state and private university staff, state agency administrators, and health professionals to plan a research agenda and coordinate grant efforts. It will need to be demonstrated that funding the requested services leads to reduced long-term health care costs, specific programmatic costs, and financial support provided by the state. It should be emphasized that projects will have greater chances of being funded by federal agencies if they include numerous and diverse collaborators. For example, the TBI Service Coordinator Early Referral Project Program Evaluation was recently funded by HRSA, and similar projects can be conducted statewide.

- Advocacy efforts should be made to **increase the number of TBI service coordinators, and to have them serve as the case managers for all persons with TBI.** Demonstrations projects should also be conducted to assess whether **flexibility in spending** is associated with improved health and decreased total state costs.
- Members of the TBI Advocacy Network should arrange meetings with all insurance and managed care companies in the state to **ensure that TBI experts serve on all of their insurance panels.**
- An analysis should be conducted to **determine the total number of Missourians seeking TBI-related behavioral treatment programs,** and the total state costs to send them to neighboring states. Efforts should be made to increase the number of such programs in the state (as well as funding for these programs), as well as to increase the visibility of existing TBI-related behavioral programs. In the short term given limited funding, it may be necessary to **develop and evaluate TBI related programs that are integrated into existing behavioral health programs,** with adequate training for program personnel.

5. Recommendations to Improve Post-Acute Services

- It will be critical to **promote the conceptualization of a TBI as a chronic health condition that requires lifelong services for non-medical issues,** rather than as an acute medical condition which can be effectively treated with short-term medical

services. This can be achieved by means of research and demonstration projects, and presentations to state and private insurance personnel, although it must be acknowledged that convincing these payors will be difficult.

- Promotion of a **case management system for persons with TBI** should be encouraged, similar to the case management system available to persons with developmental disabilities through state Regional Centers. Although persons with TBI and developmental disabilities are very different (i.e., developmental disorder from birth vs. acquired disability), both populations can benefit from case management services for life. Expansion of the current TBI service coordinators program should be considered as a model for such a program.
- At a minimum, **each Regional Center should employ a case manager with expertise in TBI.**
- **To increase the number of transitional and outpatient day treatment programs**, it will be necessary to convince state and private insurance providers of the financial benefits of such programs, in addition to personal benefit to persons with TBI. This will be most effectively done by means of demonstration and research projects.
- To address the lack of professionals trained in TBI in generalist outpatient settings, efforts should be made to **provide TBI continuing education programs to professional associations**, and particularly through telehealth networks wherever possible.
- The state should also **expand debt forgiveness programs** for rehabilitation professionals who agree to work in underserved regions of the state. It would also be useful to educate rehabilitation professionals in training programs of the existing federal debt forgiveness programs for persons who practice in designated medically underserved or mental health shortage areas.

- Research and demonstration projects should help **determine if greater flexibility in spending by case managers** (e.g., TBI service coordinators, DVR counsellors) **is associated with more significant financial savings** across all state programs.

6. Recommendations to Increase Housing, Family Support and Transportation Options

- Consider **partnering with agencies that provide housing for persons with developmental disabilities to assess the pros and cons of integrating some TBI community-based small housing units within existing programs** provided by these agencies. This is a controversial and less than ideal solution, but it may provide a way to increase availability of housing units for persons with TBI who require assistance or minimal supervision to live independently. If this model were to be adopted, it would require training for agency staff on the ways in which persons with TBI differ from individuals with developmental disabilities.
- Greater communication and partnership between TBI service coordinators and Independent Living Centers may offer options for **in-home personal assistance service through Missouri's Medicaid waiver**. It would be necessary to examine Medicaid waiver program eligibility criteria and negotiate with Medicaid to have these services made available for a greater number of persons with TBI.
- Although small single-family unit housing is optimal, it may be necessary to **develop group home options for persons with TBI in the community**. In recent years the Brain Injury Association of Missouri has begun to examine this option, and it may be necessary to develop a Brain Injury Association and family-run task force to develop an action plan to implement a group home project. In doing so, the task force would need to search for similar programs, examine their initial and ongoing funding sources, and evaluate their lessons learned in implementing community-based housing for persons with TBI. The task force may also want to

borrow from other models, including models in Scandinavian countries that use aggregated small community-based housing units with live-in support staff.

Family Support Issues

- **Evaluate the existing Early Support Partnership Program**, which is attempting to provide support and information to family members of individuals with TBI during the initial stages of hospitalization. If shown to be successful, efforts should be made to further replicate this project in all relevant hospitals across Missouri.
- **Examine the structure and implementation of early intervention programs in other states.** From this examination models or at least model elements can be aggregated into an effective program for Missouri.
- Develop **resource packets to distribute at all hospitals** that provide initial medical and rehabilitation services to patients, listing all relevant local support services. Independent Living Centers can serve as possible information repositories for local resources.
- **Develop a website that lists all available family supports by county.** This could be a section of the proposed unified TBI website and could be linked across state agencies and advocacy websites
- Work with the MO Brain Injury Association to **form more TBI support groups** in rural areas of state, particularly in northern Missouri.
- Work with the Missouri Telehealth Network to **determine if telehealth networks can be used on regular basis to coordinate state-wide TBI support groups.**

Transportation Issues

- **Develop and evaluate the efficacy and cost-effectiveness of novel transportation models for persons with TBI.** There will be a need to consider new models, and investigate other transportation models used by other states.
- **Develop novel hybrid public-private partnerships to address complex transportation problems.** It will be necessary to work with existing community transportation resources to address transportation problems, including the possibility of using state vehicles, community agency van services, and private organizations such as churches.
- **Develop web-based resources that list all transportation options by community.**
- **Re-evaluate existing Medicaid transportation reimbursement policies,** and advocate for reimbursement for travel to services other than medical care.
- **Work with Medicaid to improve the timeliness of payments for Medicaid contracted drivers.**
- **Work with Division of Vocational Rehabilitation to evaluate the utility and cost-effectiveness of home-based work options** for individuals with TBI.
- **Work with state TBI researchers to propose transportation demonstration projects to be funded through federal initiatives and programs** (e.g., the New Freedom Initiative, Department of Commerce and Department of Transportation).

7. Recommendations to Address Substance Abuse Issues

- **Advocate for more CSTAR programs** specifically for persons with TBI across all regions of the state.

- **Improve marketing for the existing substance abuse program** at Missouri Rehabilitation Center for persons with TBI, and consider advocating for transportation funds for family to attend short-term family treatment sessions.
- Require **annual training regarding TBI for Department of Mental Health substance abuse counselors**, or at a minimum have Department of Mental Health district offices **designate one TBI counselor for each office**.
- **Improve behavior management programs in substance abuse programs** to ensure participants can successfully complete these programs. This is likely to require additional training for counselors in the unique interaction of TBI and substance abuse.
- **Improve the integration of substance abuse services into existing TBI treatment programs**. This may require new training in substance abuse issues for program personnel.

8. Recommendations to Address the Needs of Underserved Populations

The needs of these traditionally underserved populations may be best served by **creating targeted interest groups and committees** to ensure that their needs are being addressed.

-Formation of a **pediatric special interest group of the MO Head Injury Advisory Council** can ensure that children's service needs receive the attention and the sustained institutional support necessary to promote effective children's programming. At present the Council addresses many pediatric issues very effectively, but a standing pediatric interest group would provide a sustained focus.

-The Missouri Brain Injury Association has been undergoing an evaluation and restructuring of its database. In concert with this reorganization of the MO-BIA database, voluntary self-identification as a racial or ethnic minority group member of MO-BIA would enable the MO-BIA **to identify and mobilize minority group**

members for effective advocacy. Ideally, a racial and ethnic minority caucus of MO-BIA would raise the visibility of minority group members in MO-BIA, and may result in greater minority participation in brain injury advocacy. Such a caucus could also speak with a stronger voice to ensure that TBI services are delivered in a culturally appropriate manner to all Missourians. Ideally, minority group members with TBI could “snowball” membership by recruiting other minority group members, which would increase the likelihood of minority group members being represented in visible and influential TBI leadership positions. This process could increase the sense of enfranchisement that minority group members feel with respect to the TBI service structure, and could result in minority group members having a seat at the table and a greater opportunity to shape Missouri’s TBI policy.

-The needs of rural Missourians with TBI are complex and extremely difficult to address because of rural resource scarcity. The Council and MO-BIA may wish to **consider partnering with MU’s Extension office and adopting novel resource-sharing strategies to reach into rural Missouri communities.** For example, the disAbility Spin resource tool (disabilityspin.org) enables individuals in Columbia to share disability-related resources economically and effectively, and this tool could be replicated in smaller rural Missouri communities where resource scarcity demands that formal and informal services and resources be shared as efficiently as possible.

-Persons with mild TBI are often released from the emergency room setting without hospitalization, so they do not typically receive any information on TBI except standard medical information about warning signs and medical risks of TBI.

Developing and distributing a very brief handout listing resources for mild TBI would enable emergency room personnel to offer resources in addition to their standard written medical instructions for patients with mild TBI. This would enable resource information to “piggyback” on the existing system of written discharge instructions at low cost and with high likely adherence by health care personnel.

9. Recommendations for Statewide TBI Action Plan

Based on these recommendations from key stakeholder groups, we propose that the Head Injury Advisory Council, Department of Health and Senior Services Bureau of Special Health Care Needs, the Brain Injury Association of MO, and other relevant groups form a partnership to put in place an action plan with key goals, timelines, and specific objectives and designees responsible for these activities. Ideally, this group would institute the TBI Advocacy Task Force, and would decide on which of the recommended steps are appropriate to target for immediate implementation. The Action Plan should detail the key plans for TBI service structure change to be targeted over the next 3-5 years, as well as the personnel and resources that will be necessary to implement the Action Plan. In this manner, key stakeholders can maintain efforts at long-term programmatic change in TBI service delivery while remaining adaptable to a changing funding and political climate.

B. Conclusions

The primary findings of this study suggest that incidence estimates for TBI in Missouri's population vary widely. However, given the most recent data available from the TBI Registry and the CDC, and accounting for the numerous biases toward under-reporting, the best estimates suggest that a total of between 18,300 and 24,832 will incur a brain injury each year, although only about one quarter of that number will be hospitalized for TBI, and a relatively small proportion will experience lifelong TBI-related disability. In 2004, an estimated 114,089 Missourians alive today have ever been medically treated for TBI. This report offered a number of relatively straightforward suggestions to ensure that Missouri's incidence and prevalence data are in keeping with CDC guidelines and are as accurate and current as they can be given the limited resources available.

The stakeholder needs assessment consisted of two parts: 1) extended phone and in-person interviews with TBI adult and child survivors, family members, and TBI service providers; and 2) a statewide series of focus groups among key stakeholder groups. By far the most common issues raised were related to *lack of TBI knowledge among agencies and service providers with whom persons with TBI must interact* (schools, human services state agencies, health care providers, etc.). A second key issue related to *poor service integration* across state agencies and other service providers. Another main theme related

to *service accessibility*. Many participants reported that even where appropriate services may exist, barriers such as difficulty navigating the system, transportation problems, or funding issues interfered with delivering appropriate services in a timely manner.

The result of these efforts is a description of issues ranging from how to estimate the population in need of TBI services in the most cost-effective manner to how Missouri can ensure that children with TBI return to schools that are prepared to serve them. This report made numerous recommendations for various TBI constituencies to consider in order to increase the effectiveness of their considerable efforts. Key issues often involved challenges related to funding, but an effort was made to generate recommendations that have maximal impact-to-investment ratio by “piggybacking” on existing service structures wherever possible. The result is a blueprint for improving Missouri’s TBI services as we embark on the 21st century, one we hope will generate considerable interest among the many Missourians affected by brain injury.

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Appendix A: Sources & Products

GOAL I: ESTIMATE THE INCIDENCE & PREVALENCE OF TRAUMATIC BRAIN INJURY IN MISSOURI

Data sources:

- Missouri Trauma Registry
- Department of Elementary and Secondary Education
- Emergency Room audits
- Acute rehabilitation hospital studies
- Missouri Model Brain Injury System data
- Jail and prison behavioral health service provider interviews
- Centers for Disease Control and Prevention relevant documents
- Other states' incidence and prevalence studies
- Peer-reviewed literature on estimating TBI incidence and prevalence

Products:

- Current estimates of Missouri's actual TBI incidence and prevalence
- Recommendations for specific actions to maintain accurate and current TBI incidence and prevalence data for Missouri

GOAL II: INTERVIEW INDIVIDUALS WITH BRAIN INJURY, THEIR FAMILIES, AND OTHER KEY STAKEHOLDERS

Data Sources:

- survey materials adapted from previous HRSA grants in Maryland and Iowa to conduct interviews with adults and children with TBI and their families, service providers, and other relevant agency personnel
- surveys focused on:
 - sociodemographic characteristics
 - factors related to injury
 - current health status
 - behavioral issues
 - health care resources
 - service needs and barriers

Products:

- broadly based survey data from 428 phone surveys that takes into account perspectives of multiple stakeholder groups
- identification of key service structure barriers from survivor and family perspectives
- key TBI-related problems from provider and administrator perspectives

GOAL III: IDENTIFY BRAIN INJURY SERVICE GAPS IN MISSOURI

Data sources:

- 1999 TBI service matrix developed by state agencies serving persons with TBI
- Information from previous focus groups

- Data generated from new survivor, family, and stakeholder focus groups and interviews
- Recommendations from brain injury support groups

Products:

- Detailed descriptions of service gaps and the reasons those gaps persist
- Description of unmet needs among vulnerable TBI subpopulations
- Systematic recommendations and action plans for implementing a statewide agenda to close TBI service gaps

Appendix B: Anecdotal & Qualitative Data

Anecdotal Reports:

- *Mother of a Child TBI Survivor:* A mother reported that her 17-year old son incurred a TBI and was unconscious for four days and in the hospital four months. Her son goes to school part-time and works part-time. The mother noted that her son has motor problems, memory loss, trouble sleeping, anxiety attacks, sudden mood swings, loss of energy, and trouble concentrating. His level of functioning almost independent, but he needs help with scheduling and reminders, as well as supervision in the kitchen. Initially, he had private insurance coverage, but now he has no insurance coverage, and the mother cannot afford to pay the bills. Her son is not eligible for Medicaid. She said that “he’s having a lot of problems with the school. We’re having trouble finding someone to stay with him after school, and there are no public services available. He now attends a special school. ...the Brain Injury Association and the governor’s forum have been great resources.” She also noted that she was unable to find resources through the Missouri Department of Mental Health.
- *Mother of a Child TBI Survivor:* A mother reports that her 11-year old son has a severe TBI from a vehicle accident while riding his bicycle. Her son goes to school full-time, but experiences motor impairment, memory loss and sleep disturbance, impulsiveness, and trouble concentrating. He also needs assistance with fine motor skills. He currently has private insurance, but he cannot receive rehabilitation (occupational therapy, speech therapy, physical therapy), as the coverage stopped after 2 years. He has fallen twice because of balance problems. “My problem is . . . how am I supposed to find out what is available?! When looking at the Internet, I look up Head Injury Advisory Council, and I cannot find it. It’s not at the top. I have to search and go 2 pages down. Billboards are totally not a way to reach the public... Also, there’s no common place for children to go after acute care,” the mother revealed.
- *Adult Survivor:* A man in his 50s received a TBI when he fell off scaffolding at work. He was in the hospital for a few days, and did not receive rehabilitation. Since his TBI, he is easily distracted and has bouts of depression. He owns his own business, but when he went back to work after the injury, he had difficulty due to irritability and

needing others to help him with tasks. He currently sees a Neuropsychologist, stating “this is the best experience of all the services I have received. Mostly, because he listens to me.” The survivor says he has a major problem with keeping his service providers informed about what is going on. He believes that he needs a central coordinator to help “steer the boat” on his care. “If you don’t keep the patient informed, you won’t get support. I have no trust of the entire system. No one knows enough to help . . . there is no help.”

- *Family Member of Adult Survivor:* A grandmother reported that her adult grandson experienced a severe TBI from a fall. He lives in a supervised community residence and volunteers in the community. He has difficulty with motor skills, seizures, severe headaches, memory loss, trouble sleeping, sudden mood swings, loss of energy, trouble concentrating, and mental health problems. He needs help taking medications and has trouble with keeping his balance. He was struck by a car two more times after the initial TBI due to balance problems. This caused more injuries and the need for corrective surgery. “His problem is that Medicaid is so limited that he goes without it sometimes. There needs to be free counseling and coping support group for family members and caregivers,” she stated.
- *Service Provider:* A neuropsychologist in an urban area serves about 70 persons with TBI per year, where he provides educational services and family and individual counseling services. He noted that the primary problem in providing services to people with TBI is the “lack of insurance coverage.” He believes there is fragmentation of care for persons with TBI, and that “they fall through the cracks. They’re not identified, and most providers are unsure what to do, while the survivor sits.” Coordination between state public policy and community service delivery is problematic due to limits on funding for TBI service delivery. He stated further that “the system is not effectively meeting the needs for people with TBI because [survivors and families] don’t know about the services available.”

Qualitative Themes:

As the research team collected data via interviews, qualitative analyses were conducted to categorize the data into the prominent areas of concern and need for TBI survivors and their families. Based upon a consensus process among primary project interviewers, the team derived main categories of responses that describe main barriers and problem areas. Team members then entered the data into a secure electronic database system using these response categories. Once the surveys were completed, the research team analyzed that data with descriptive statistical analyses to identify primary problems described by interviewees.

The following list describes the most frequently cited concerns expressed by survivors and family members.

Main Barriers and Problem Areas:

1. Lack of Funding Sources

- While funding may be available before age 22, there is a limited number of funding sources after the age of 22.
- Inner city TBI survivors spoke about problems with attaining disability eligibility and problems with securing housing through Section 8 (government housing assistance).

2. Accessibility to Services

- Transportation and access to TBI services in rural areas is very problematic, as public transportation is limited and difficult to navigate when it is available.
- There is a significant lack of funding for TBI services, especially in South St. Louis County and in rural areas of MO.

3. Access to and Affordability of Transportation

- Transportation was the major issue reported in the urban center of St. Louis. Interviewees frequently cited the lack of convenience and lack of accommodation among public transportation services.
- Many interviewees felt they were denied transportation if they lived near a bus line. Despite this proximity, persons with brain injury persons noted that

memory and physical limitations prevented them from having realistic access to existing public transportation resources.

4. Information about TBI and Services

- There is a lack of information sources about TBI and services, especially regarding SSI, eligibility for disability, and funding sources.
- There is a need for more awareness for the public and survivors about high levels of alcohol and drug abuse treatment options for TBI survivors.

5. The General Public, Schools, and Service Providers Lack TBI Awareness

- One family member, who is an educator, noted that he finds the school system to lack knowledge and awareness about the needs of TBI survivors and their families.
- There are no resources for children whose parents have a TBI; children may be at increased risk for adjustment problems or may remain isolated from needed support services.

6. Post-Acute TBI Services/Continuity of Care

- Family members and survivors expressed fears about how the survivor will get along after family members are deceased. There is no transitional program for survivors whose family support members are deceased.
- Many of the survivors and family members noted that TBI needs to be recognized as a life-long disability in order to treat TBI-related behavioral issues as they arise throughout the life span.

7. Poor Communication between Service Providers

- Many respondents cited poor coordination or communication among service providers as a primary source of frustration and inefficiency.

- Some family members stated that Missouri’s governmental agencies need to know about other types of treatments beyond traditional/medical (i.e., alternative treatments for persons with TBI).
- Service staff noted that hospitals seem unwilling or unable to share information about TBI support groups.

8. Long Waiting Lists for Services and Need for More Service Providers

- Several TBI survivors noted they wait for funding too long to receive care or supportive services.
- There is a lack of follow-up with TBI across life transitions.
- Some survivors complained private and public sector programs treat TBI as an acute crisis rather than a long-term disability because they lack the budgets to provide appropriate long-term services.

9. Lack of Housing for Survivors

- Community housing is lacking; there is only apartments for seniors, nursing homes, persons with developmental disabilities, and low-income housing, which raises safety concerns among the vulnerable population of TBI survivors.
- Independent living options or help in the home is almost non-existent. Clients resort to living in Senior Housing or nursing homes in violation of Olmstead Act principles.

Frequently Cited Potential Solutions from Survivors and Family Members

1. Insurance companies need to broaden coverage for TBI and extend it past the acute injury period.
2. Medicaid needs to broaden coverage for therapies and serve persons 22 and older at the time of their injury.
3. Increase education and training in TBI issues for state agency personnel.
4. Increase Medicaid coverage for transportation to support independent living needs, such as shopping and therapies.
5. Enhance convenience of transportation (pick-up/delivery times).

6. Increase Public Service Announcements (PSAs) regarding TBI.
7. Provide better information to TBI survivors and families early in the treatment process regarding TBI services (support groups, medical and mental health, vocational and schooling resources).
8. Provide information to teachers and administrators regarding TBI and children's service needs.
9. Create a follow-up system for TBI service delivery for as long as a person continues to have TBI-related disability.
10. Create a one-stop shop system for TBI services to create more efficient service delivery as well as better communication between providers.
11. Increase the number of Head Injury Service Coordinators and other professionals who deal with TBI survivors and families.
12. Provide more resources for families/guardians in dealing with TBI survivors and their own needs (parents, spouses, etc.).

These findings and recommendations are consistent with findings from other sources, such as input given at statewide TBI conferences. Findings from these surveys also converge with data from focus groups conducted in this needs assessment process, lending further validity and weight to these issues as the primary concerns of persons with TBI and their families. A discussion of the findings from those focus groups follows in section VII of this report.

Appendix C: Additional Incidence Data

High-Range TBI Incidence Estimates for Missouri

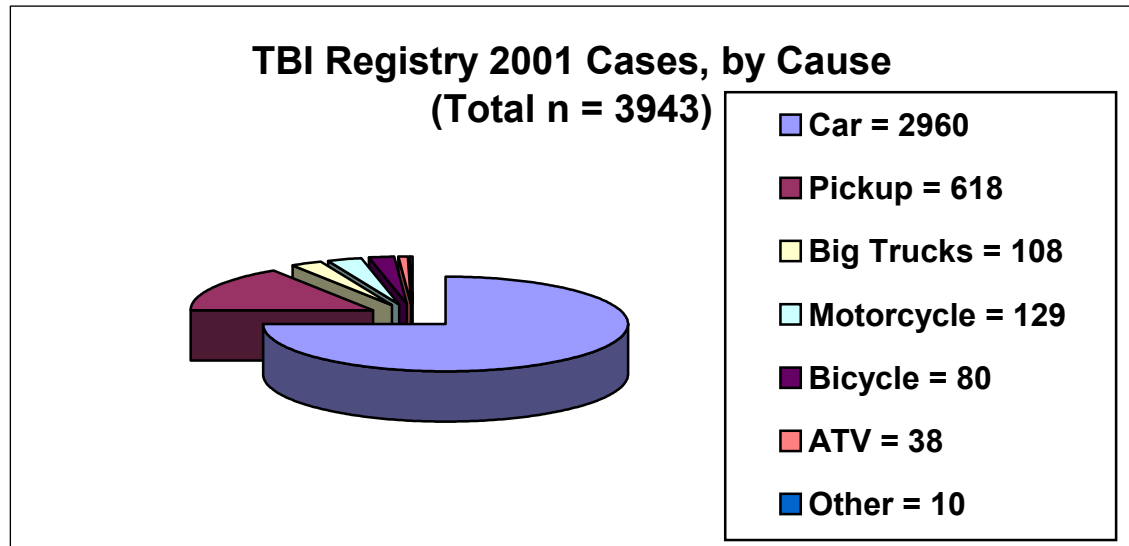
Among the highest estimates of TBI incidence is the frequently-cited figure of 2 million new brain injuries per year across the United States as a whole (Brain Injury Association of the United States of America). Assuming that TBI risk is distributed equally across all members of the U.S. (and this is a questionable assumption), and assuming that the figure of 2 million new TBIs per year remains stable (also questionable), Missouri's share of the 2 million new TBIs each year should be roughly equal to the proportion of Missourians in the U.S. population. Missouri's estimated 2003 population is 1.96% of the whole (Missouri's population is estimated at 5,704,484 and the United States 2003 population as a whole is estimated at 290,809,777). Using these assumptions, an estimated 39,200 Missourians would sustain a TBI each year. However, estimates this high are generally not backed by current empirical data and therefore it is difficult to argue for service structures to meet this broad a need in the absence of such supporting data.

Mid-Range TBI Incidence Estimates for Missouri

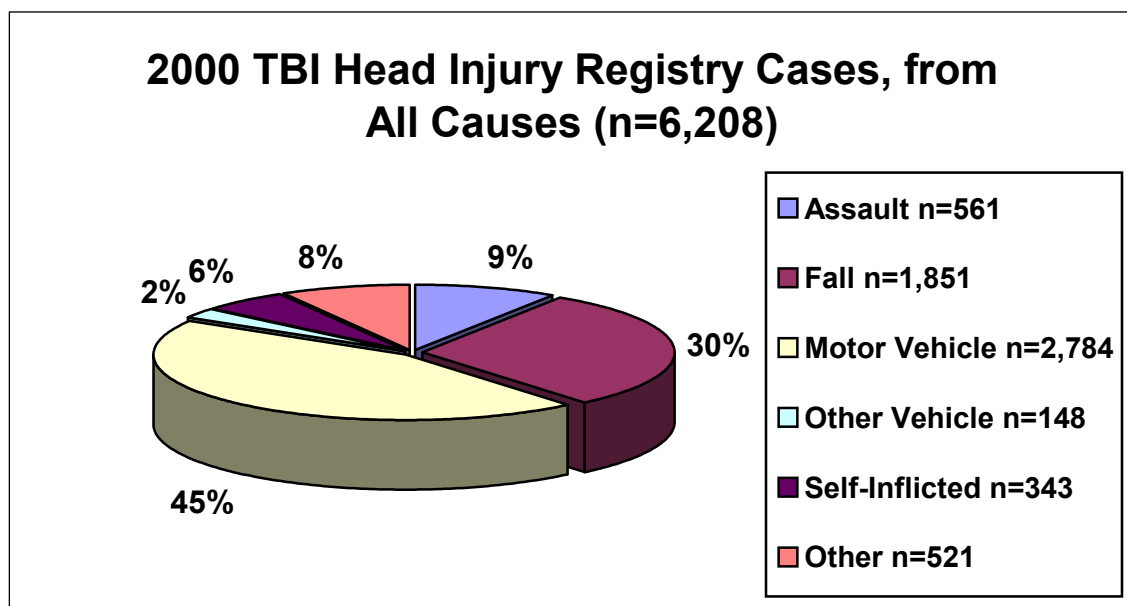
The Centers for Disease Control and Prevention (CDC) has published state-by-state data on TBI based on TBI Registries, which are in place in approximately 40% of all states (Walker, Stevenson, Logan & Leukefeld, 2003). According to these data, the CDC estimates that 4,575 Missourians were hospitalized and survived TBI in 1998, the last year for which data were available (CDC, 2004). However, because the CDC estimates that 75% of all new TBI cases are persons with mild TBI who are rarely hospitalized (CDC, 2003), the total estimated hospitalized and non-hospitalized cases per year would be 18,300, including the 4,575 survivors who received medical treatment and are accounted for in the Registry and 13,725 whose cases were not reported.

Low-Range TBI Incidence Estimates for Missouri

The Trauma Registry is a key tool for estimating TBI incidence, since it comes from actual reported cases. This registry is maintained by the Missouri Department of Health



and Senior Services in an effort to document the new cases of TBI reported each year. The Registry receives reports from select hospitals statewide, and provides one source of information that can contribute to Missouri TBI incidence estimates. For the year 2001 (the last year for which Registry figures are posted), the Registry recorded a total of 3,943 new TBI cases from vehicle crashes alone, mostly related to car and pickup truck crashes.



The Missouri Head and Spinal Cord Injury Registry estimates TBI from all causes. In 2000, the last year for which head injury data are posted by the Head and Spinal Cord Registry, a total of 6,208 new TBI cases were reported from all causes. However, these data rely almost entirely on patients who were hospitalized at the time of their injury, and therefore they do not include persons who were not hospitalized, or who were hospitalized at non-reporting hospitals. Therefore, the majority of TBIs (an estimated 75%, according to the CDC) are not counted in these estimates. Cases also go undetected if the primary diagnosis is other than TBI (e.g., spinal cord injury or multi-trauma) and the brain injury is only detected later after the effects of acute treatment measures such as intensive pain medications, intubation and chemical paralyzation no longer interfere with accurate TBI diagnosis. Thus, the 6,208 figure does not include persons with spinal cord injury or multi-trauma whose brain injury only becomes evident later during the rehabilitation process.

Appendix D: Survey Measures

Adult TBI Survivor

Child TBI Survivor

Family Member or Guardian

TBI Service Provider

Date	Time	Contact	Comments

IF INTERVIEWING BY PHONE, START HERE:

Hello, my name is _____. I am calling for the Department of Health Psychology at the University of Missouri-Columbia. May I speak with _____? As part of a statewide needs assessment of traumatic brain injury services, I would like to interview you regarding your experiences as a survivor of traumatic brain injury. The interview should only last ~ 20-30 minutes.

IF INTERVIEWING IN-PERSON, START HERE:

Before we begin, let me assure you that all of your responses will be kept strictly confidential. If I ask you any questions that you do not want to answer, just let me know and I will go on to the next section.

1. Are you the person in your home who has the brain injury?

Yes: Do you have any questions before we get started?

No: Could you please tell me the first name of the person in your home that uses these services? _____

What is your relationship with this person? _____

First, I would like to start with some background questions.

2. How old (are you/is “Survivor’s Name”)? _____

3. Do you consider yourself a member of a minority group?

Yes: What group would that be? _____

No: Go to Question # 4.

4. What town (do you/does “Survivor’s Name”) live in (or closest to)?

5. How many years of school (have you/has “Survivor’s Name”) completed?

6. (Are you/Is “Survivor’s Name”) currently employed?

Yes: What is (your/“Survivor’s Name”) job? _____

No: Is there a specific reason why (you are/“Survivor’s Name” is) not working?

7. How did (you/“Survivor’s Name’s”) brain injury occur?

8. When did it occur? _____

9. (Were you/Was “Survivor’s Name”) hospitalized at the time?

Yes: For how long? _____

No: Go to Question # 10.

10. Did (you/“Survivor’s Name”) receive rehabilitation?

Yes: What kind? _____

No: Go to next section.

11. How many times in the past month have you been unable to accomplish goals because of transportation concerns? _____

Now I have so me questions about how the brain injury may have affected (Your/Name’s) life.

12. (Do you/Does “Survivor’s Name”) have any physical difficulties as a result of the brain injury?

Yes: Could you tell me what these are?

No: Go to Question # 13.

13. (Do you/Does “Survivor’s Name”) have any difficulties remembering things as a result of the brain injury?

Yes: Could you give me an example?

No: Go to Question # 14.

14. (Do you/Does “Survivor’s Name”) have any difficulties organizing your daily activities as a result of the brain injury?

Yes: Could you give me an example?

No: Go to Question # 15.

15. (Do you/Does “Survivor’s Name”) have any difficulties making decisions as a result of the brain injury?

Yes: Could you give me an example?

No: Go to Question # 16.

16. (Do you/Does “Survivor’s Name”) have any emotional difficulties as a result of the brain injury?

Yes: Could you tell me what these are?

No: Go to Question # 17.

17. (Do you/Does “Survivor’s Name”) have any learning difficulties as a result of the brain injury?

Yes: Could you give me an example?

No: Go to Question # 18.

18. (Were you/was “Survivor’s Name”) in school at the time of the brain injury?

Yes: How did the brain injury affect (your/“Survivor’s Name’s”) ability to go to school?

No: Go to Question # 19.

19. (Were you/Was “Survivor’s Name”) employed at the time of the brain injury?

Yes: How did the brain injury affect (your/“Survivor’s Name’s”) ability to work?

No: Go to next section.

Now I would like to ask you about changes that may have happened in (your/“Survivor’s Name’s”) life because of the brain injury.

20. (Have you/Has “Survivor’s Name”) had to make any changes in (your/his or her) lifestyle because of the brain injury?

Yes: Can you give me an example?

No: Go to Question # 21.

21. Are there any activities that (you/"Survivor's Name") can't participate in any more?

Yes: What are they?

No: Go to Question # 22.

22. Has (your/"Survivor's Name") family changed in any way as a result of the brain injury?

Yes: In what ways?

No: Go to Question # 23.

23. (Do you/"Survivor's Name") live by (yourself/his or herself)?

Yes: Is there someone who helps take care of things?

Yes: Who is it? _____

No: Go to Question # 24.

No: Who do you live with? _____

24. Has (your/"Survivor's Name") living situation changed since the brain injury?

Yes: Where did (you/"Survivor's Name") live before the injury?

No: Go to Question # 25.

Now I want to ask you a few questions about services provided to persons with Traumatic Brain Injury (TBI).

25. What services (are you/is “Survivor’s Name”) currently using?

PROBE: Ask, “are there any others” until participant says “no.”

A. Service: _____

B. Service: _____

C. Service: _____

D. Service: _____

E. Service: _____

F. Service: _____

Go to Question # 26.

	Provider A	Provider B	Provider C
26. Who provides this service?	_____	_____	_____
	_____	_____	_____
27. How (do you/does “Survivor’s Name) pay for this service?	_____	_____	_____
	_____	_____	_____
28. How far (do you/”Survivor’s Name”) have to travel to get this service?	_____	_____	_____
	_____	_____	_____
29. How often (do you/does “Survivor’s Name”) use this service?	_____	_____	_____
	_____	_____	_____

	Provider D	Provider E	Provider F
30. Who provides this service?	_____	_____	_____
	_____	_____	_____
31. How (do you/does "Survivor's Name") pay for this service?	_____	_____	_____
	_____	_____	_____
32. How far (do you/"Survivor's Name") have to travel to get this service?	_____	_____	_____
	_____	_____	_____
33. How often (do you/does "Survivor's Name") use this service?	_____	_____	_____
	_____	_____	_____

34. How (do you/does "Survivor's Name") learn about the services that are available?

35. (Do you/"Survivor's Name") have trouble getting information about where to get services or help?

Yes: Can you give me an example?

No: Go to Question # 36.

36. Are there services that (you need/"Survivor's Name" needs) that (you are/s/he is) not getting?

PROBE: Ask, "are there any others" until participant says "no."

A. Service: _____

B. Service: _____

C. Service: _____

D. Service: _____

E. Service: _____

37. For each of the needs you just mentioned, would you tell me why (you are/"Survivor's Name" is) not getting this service or help? What is the main barrier?

A. Service: _____

B. Service: _____

C. Service: _____

D. Service: _____

E. Service: _____

38. What has been (your/"Survivor's Name's") best experience with the services that (you have/s/he has) received?

39. What has been (your/"Survivor's Name's") worst experience with the services that (you have/s/he has) received?

Finally, I have some questions about how (you/"Survivor's Name") service providers work together with each other.

40. (Do your/Does "Survivor's Name") different service providers communicate effectively with each other?

Yes: Can you give me an example?

No: Can you give me an example?

41. Who is responsible for keeping the different people (you see/"Survivor's Name" sees) informed about what is going on?

42. Do you think that (your/"Survivor's Name's") service providers work well together to give (you/him or her) the best possible care?

Yes: In what ways?

No: What could they be doing better?

43. Would (you/"Survivor's Name") like to be more involved in (your/his or her) treatment plan?

Yes: In what ways?

No: Go to Question # 44.

44. Are there any additional comments you would like to make about the services you receive or would like to receive?

We appreciate the time you have given us to help with this important effort.

Thank you!

CHILD TBI SURVIVOR SURVEY

Date	Time	Contact	Comments

IF INTERVIEWING BY PHONE, START HERE:

Hello, my name is _____. I am calling for the Department of Health Psychology at the University of Missouri-Columbia. May I speak with _____? As part of a statewide needs assessment of traumatic brain injury services, I would like to interview you regarding your experiences as a survivor of traumatic brain injury. The interview should only last ~ 20-30 minutes.

IF INTERVIEWING IN-PERSON, START HERE:

Before we begin, let me assure you that all of your responses will be kept strictly confidential. This means that we respect your privacy and will not share your answers with others. If there are any questions that you do not want to answer, just let me know and I will go on to the next question.

(Interviewer needs to indicate who is filling out the survey)

- ☐ Child
- ☐ Parent
- ☐ Someone else in the family
- ☐ Friend
- ☐ The person who takes care of the child
- ☐ TBI Staff
- ☐ Other (Please state _____)

1. Which county in Missouri do you live in?

2. Are you a boy or a girl? *(Interviewer circles one)*

Boy

Girl

3. How old are you now?

4. How old were you when you were hurt?

5. How did you get hurt?

_____ Car crash or other crash

_____ Riding a bike

_____ Hit by a car

_____ Almost drowned

_____ Falling down

_____ Someone else hurt them

_____ Shot

_____ When they were playing

_____ Do not know

_____ Other (*Please specify*) _____

6. Do you go to school? (*Interviewer Circles One*)

Yes

No

7. Does a teacher come to your house? (*Interviewer Circles One*)

Yes

No

8. What grade are you in?

9. Do you have any special help? (*Interviewer Circles One*), (*If no go to question #11*)

Yes

No

Don't know

10. What kind of special help do you have?

_____ Resource room

_____ Occupational Therapy

_____ Tutor

_____ Speech Therapy

_____ Reading teacher

_____ Physical Therapy

_____ Counselor

_____ Don't know

_____ Other (*Please specify* _____)

11. What subject are you best at in school?

12. What subject is the hardest for you in school?

13. Do you have a best friend? (*Interviewer Circles One*)

Yes No

13. Do you have other friends too? (*Interviewer Circles One*)

Yes No

14. Was it hard to go back to school after you were hurt? (*Interviewer Circles One*)

Yes No

15. What was hard about it?

16. What do you do when you are not in school? (*Try to get the three that they do the most*)

- _____ Play with friends
- _____ Play with their pet
- _____ Play video games
- _____ Watch TV
- _____ Take naps
- _____ Visit their family
- _____ Read books
- _____ Ride their bike
- _____ Help their parents
- _____ Play by myself
- _____ Listen to music
- _____ Don't know
- _____ Other (*Please specify what they do* _____)

17. Is there anything that you wish you could do, but cannot because of the injury?

18. What stops you from being able to do what you want?

- ☐ Too tired
- ☐ No one helps me
- ☐ It is too hard
- ☐ Too busy
- ☐ Don't feel good
- ☐ Sad
- ☐ Can't move well
- ☐ No one to play with
- ☐ Don't know
- ☐ Other(*Interviewer needs to specify*_____)

19. Has anything changed since you were hurt?

20. What makes you happy?

21. What makes you sad?

22. What would make your life better?

23. Is there anything else you would like to tell me?

Thank you very much for giving me the chance to speak with you.

FAMILY MEMBER OR GUARDIAN SURVEY

Date	Time	Contact	Comments

IF INTERVIEWING BY PHONE, START HERE:

Hello, my name is _____. I am calling for the Department of Health Psychology at the University of Missouri-Columbia. May I speak with _____? As part of a statewide needs assessment of traumatic brain injury services, I would like to interview you regarding your experiences as a family member of a survivor of traumatic brain injury. The interview should only last ~ 20-30 minutes.

IF INTERVIEWING IN-PERSON, START HERE:

Before we begin, let me assure you that all of your responses will be kept strictly confidential. If I ask you any questions that you do not want to answer, just let me know and I will go on to the next section.

1. What county do you live in?

2. What is your relationship with the individual with Traumatic Brain Injury?

The following questions are about the basic information about the person who sustained the injury.

3. How old are they now?

4. What is their gender?
- _____
5. What was their age when the injury occurred?
- _____
6. How did the injury happen? (Mark whatever applies)
- ____ Motor Vehicle
- ____ Bicycle
- ____ Near Drowning
- ____ A Fall
- ____ Assault/Abuse
- ____ Sports
- ____ Unknown
- ____ Other _____
7. What was the extent of the injury? (To what degree)
- _____
8. What is their current living condition?
- ____ Living alone
- ____ Living with family
- ____ Living with non-relatives
- ____ Rehab facility
- ____ Long-term care facility or nursing home
- ____ Supervised community residence
- ____ Other
9. What is his/her current employment status? (*If unemployed, go to question 11*)
- _____
10. What type of work is he/she currently involved in?
- _____
11. Is their job status higher, lower, or the same since their injury?
- _____

The following questions deal with effects in behavior the individual might have experienced since sustaining the injury.

12. Has he/she ever experienced any of the following conditions? (*Mark all that apply*)

☐ Rashes
☐ Difficulty of movement (ex. Bending of knee, hip, elbow joints)
☐ Seizures
☐ Severe headaches
☐ Memory loss
☐ Trouble sleeping
☐ Anxiety attacks
☐ Sudden mood swings
☐ Loss of energy
☐ Trouble concentrating
☐ Other _____

13. During the past month, has he/she ever lost their temper?

Yes (*If so how many times*)

No

14. During the past month, has he/she consumed any alcoholic beverages such as beer, wine, or liquor?

Yes (*If so how many times*)

No

15. During the past month, has he/she been stubborn, sullen, or irritable?

Yes (*If so how often*)

No

16. How good is his/her memory compared to people of the same age that do not have any injuries?

The following questions are concerned with the severity of the injury and the effect it has had on everyday activities.

17. Does he/she have the ability to open their eyes?

Yes (*Mark all that apply*)

- ☐ Opens his/her eyes on their own
- ☐ Opens their eyes in response to speech or sensory stimulation
- ☐ Opens eyes when in pain

No

18. What is his/her verbal ability?

- ☐ Oriented speech (Normal everyday speech)
- ☐ Confused speech (Answers are delayed and/or disoriented)
- ☐ Inappropriate speech (Shouting, swearing, no conversation possible)
- ☐ Unable to speak
- ☐ Tracheotomy tube present

19. What is his/her best motor response?

- ☐ Follows simple commands
- ☐ Pulls examiner's hand away when pinched
- ☐ Pulls a part of his/her body away when pinched
- ☐ Flexes body inappropriately to pain
- ☐ Pain results in extension of a limb
- ☐ None

20. Does he/she know how and when to feed themselves? *Ignore movement disability.*

- ☐ Completely
- ☐ Partially
- ☐ Minimally
- ☐ Not at all

21. Does he/she know how and when to use the bathroom?

- ☐ Completely
- ☐ Partially
- ☐ Minimally
- ☐ Not at all

22. Does he/she know how and when to groom his/herself?

- ☐ Completely
- ☐ Partially
- ☐ Minimally
- ☐ Not at all

23. Is his/her level of functioning completely independent, or is some assistance required?

_____ Completely independent

_____ Some assistance required (*Ask what assistance is required*)

The following questions are about medical care and services that are provided to the person with the head injury.

24. What was the source of payment for his/her medical care? (*Check all that apply*)

_____ Medicaid

_____ Medicare

_____ Private insurance

_____ Indian Health Service

_____ Health Maintenance Organization (HMO)

_____ Worker's Compensation

_____ Veteran Insurance

_____ CHAMPUS

_____ Personal funds/Self paid

_____ Not paid

_____ Other, specify _____

25. Does he/she currently have any kind of health care coverage, including health insurance, prepaid plans such as health maintenance organizations or government plans such as Medicaid?

_____ Yes

_____ No

_____ Unknown

26. Was there a time after sustaining the injury that he/she needed to see a doctor, but could not because of the cost?

_____ Yes

_____ No

_____ Do not know

27. Has he/she received medical care from a physician for conditions directly resulting from his/her head injury?

☐ Yes

☐ No

☐ Unknown

28. How many times has he/she been seen by a physician for conditions resulting from his/her head injury?

29. For what conditions did he/she see a physician or other health professional?

30. Has he/she ever been hospitalized over night for any of these conditions?

☐ Yes

☐ No (*Go to question # 31*)

31. For what conditions was he/she hospitalized over night?

32. What types of services is he/she receiving currently?

33. Since the time of the injury, what are all of the types of services that he/she has received?

34. Did you have trouble finding out about available services in your area?
____ Yes

How did you go about finding out about available services in your area?

____ No (*Go to question 35.*)

35. Have there been any services that were never received?

36. Do you have any comments and/or suggestions?

Thanks for you time and cooperation!

TBI SERVICE PROVIDER SURVEY

Date	Time	Contact	Comments

IF INTERVIEWING BY PHONE, START HERE:

Hello, my name is _____. I am calling for the Department of Health Psychology at the University of Missouri-Columbia. May I speak with _____? As part of a statewide needs assessment of traumatic brain injury services, I would like to interview you regarding your role as a service provider for survivors of traumatic brain injury. The interview should only last ~ 20-30 minutes.

IF INTERVIEWING IN-PERSON, START HERE:

Before we begin, let me assure you that all of your responses will be kept strictly confidential. If I ask you any questions that you do not want to answer, just let me know and I will go on to the next section. I would like to begin with some basic information about you and your organization.

1. What is your job title (specify profession of service provider)?

Rehabilitation Services:

1. Assistive Technologist
2. Case Manager
3. Education/Special Education
4. Nursing
5. Occupational Therapist
6. Orthotics/Prosthetics
7. Physician (MD & DO)
8. Physiatry (Rehab Doctor)
9. Physical Therapist
10. Program Administrator
11. Psychologist
12. Neuropsychologist
13. Substance Abuse Counselor

14. Residential Services Coordinator
15. Social Worker
16. Speech and Language Therapist
17. Recreation Therapist
18. Vocational Counselor

Employment Services:

19. Pre-Vocational Service Provider
20. Vocational Counselor
21. Job Accommodations
22. Extended Supports
23. Career Counselor/Guidance
24. Employment Advocate
25. Other: _____

2. Where is your organization located (**NAME and ADDRESS w/ZIP CODE**)?

3. What geographical area do you serve?

4. What is the age range of the people you serve?

5. Approximately, how many people do you serve per year?

6. Approximately, how many people with brain injuries do you serve per year?

7. Is traumatic brain injury your main area of service, as an individual provider?

Yes: Go to Question # 8.

No: What is your main area of service?

8. Do you have training in dealing with survivors of traumatic brain injury?

Yes: What type of training?

No: Go to Question # 9.

Now, I would like to know about some of the more specific aspects of the services your organization provides.

9. Do you serve people with other kinds of disabilities?

Yes: What other types of disabilities?

No: Go to Question # 10.

10. Does your organization have programs or services specifically for people with brain injuries who are racial, cultural, or linguistic minorities?

Yes: Please briefly describe the program(s) and the target population

No: Go to Question # 11.

11. How are people with brain injuries referred to your organization?

_____ Self-referrals

_____ Family members or care-givers

_____ Walk-ins

_____ Professional referrals (physicians, therapists, social workers, or other)

_____ State agencies (please specify) _____

_____ Private service providers (please specify) _____

_____ Other (please specify) _____

12. Do you provide therapy services (e.g., Physical Therapy, Occupational Therapy, Speech Therapy)?

Yes: Can you describe this service?

No: Go to question # 13.

13. Do you provide educational services?

Yes: Can you describe this service?

No: Go to question # 14.

14. Do you provide community living services?

Yes: Can you describe this service?

No: Go to question # 15.

15. Do you provide employment related services?

Yes: Can you describe this service?

No: Go to question # 16.

16. Do you provide family or individual counseling services?

Yes: Can you describe this service?

No: Go to question # 17.

17. Do you provide case management services?

Yes: Can you describe this service?

No: Go to question # 18.

18. Are there any specific problems you face in providing these types of services to people with brain injury?

(NOTE: If provider answered “No” to questions 12-17, go to question # 19).

Yes: Can you tell me what these are?

No: Go to question # 19.

Improving public awareness about traumatic brain injury has been identified as an important goal for the state of Missouri.

19. Are you involved in any specific activities aimed at increasing public awareness of traumatic brain injury?

Yes: Can you tell me what these are?

No: Go to question # 20.

20. What do you think has been successful in the past in helping the general public understand traumatic brain injury?

Coordination of services has been seen as an important component of a services system for people with traumatic brain injury that could use improvement. Now, I would like to ask you a few questions about your experiences with several aspects of coordination.

21. How does your organization coordinate with state agencies?

22. How does your organization coordinate with private service providers?

23. Do believe that there is fragmentation of care for people with traumatic brain injury?

Yes: In what ways?

No: Go to question # 24.

24. Is there duplication of care for people with traumatic brain injury?

Yes: In what ways?

No: Go to question # 25.

25. Do you think that people with traumatic brain injury sometimes fall through the cracks?

Yes: In what ways?

No: Go to question # 26.

26. Can you give me any examples of planning at the community level related to traumatic brain injury services that have worked to improve the quality of care?

27. Do you believe that there is coordination between state public policy decisions and community agencies' service delivery in regards to traumatic brain injury services?

Yes: Can you give me an example?

No: Can you tell me where coordination is lacking the most?

Now I have some questions about the accessibility of traumatic brain injury services in the state of Missouri. For each of the following statements that I read, I would like you to indicate whether you agree or disagree.

28. Accessibility to traumatic brain injury services is determined by the part of the state that someone lives in. Do you . . .

1. strongly agree
2. agree
3. neutral
4. disagree
5. strongly disagree

29. Accessibility to traumatic brain injury services is determined by the availability of experienced professionals who are trained in traumatic brain injury. Do you . . .

1. strongly agree
2. agree
3. neutral
4. disagree
5. strongly disagree

30. Accessibility to traumatic brain injury services is determined by funding availability. Do you . . .

1. strongly agree
2. agree
3. neutral
4. disagree
5. strongly disagree

31. Can you think of any other barriers which limit the accessibility of traumatic brain injury services in the state of Missouri.

Now I would like you to make some overall assessments of the service system.

32. Do you think the system is effectively meeting the needs of the people with traumatic brain injury and their families?

Yes: Go to Question #33.

No: Why not?

33. What do you think are the strongest aspects of the service system for people with traumatic brain injury?

34. What do you think are the weakest aspects of the service system for people with traumatic brain injury?

35. Are there services that people with traumatic brain injury need which they cannot receive in the state of Missouri?

Yes: What specific services are they unable to get?

Where are they going for these services instead?

No: Go to question # 36.

36. Do you think people with traumatic brain injury and their families are able to give input into their care?

Yes: Can you give me examples?

No: Why not?

37. Are there mechanisms in place for quality assurance?

Yes: Can you tell me what some of these are?

No: What mechanisms should be in place that are not?

38. If funding was not an issue, what change would you make in services for people with traumatic brain injury in your area?

39. Again, if funding was not an issue, what change would you make at the state level?

40. What do you, as a service provider, feel is the greatest area of unmet need for individuals and families dealing with traumatic brain injury in the state of Missouri?

41. What, in your opinion, would make it possible for your organization to better serve people with brain injuries and their families in the state of Missouri?

42. Do you have any other comments or recommendations?

Thank you for your assistance and cooperation.